

# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2016

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## HEARINGS BEFORE A SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS HOUSE OF REPRESENTATIVES ONE HUNDRED FOURTEENTH CONGRESS FIRST SESSION

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### PART 7 OUTSIDE WITNESS TESTIMONY



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Written Testimony  
Of  
Governor Val Panteah  
Pueblo of Zuni  
Zuni, New Mexico  
To  
House Committee on Appropriations  
Subcommittee on Labor, Health & Human Services, Education and Related  
Agencies

March 25, 2015

Chairman Cole, Ranking Member DeLauro and Members of the Subcommittee, thank you for giving me the opportunity to submit my testimony for the record on the FY 2016 Labor, Health and Human Services, Education and Related Agencies appropriations bill. It is an especially great honor to submit my comments to Chairman Cole's committee, a proud member of the Chickasaw Nation.

Keshi. Hello. The Pueblo of Zuni is located about 150 miles from Albuquerque, New Mexico in McKinley and Cibola Counties in the western part of the state. Zuni Pueblo is the largest of the nineteen New Mexican Pueblos, covering more than 700 square miles and with a population of over 10,000.

We are considered the most traditional of all the New Mexico Pueblos, with a unique language, culture, and history that resulted in part from our geographic isolation. With perhaps 80% of our workforce involved in making arts, we are indeed an "artist colony." Our main "industry" is the production of arts, including inlay silverwork, stone "fetish" carving, pottery, and others of which we are world famous. Most of Zuni's residents live in the main village of Zuni and the nearby "suburb" community of Blackrock. Zuni is a sovereign, self-governed nation with our own constitutional government, courts, police force, school system, and economic base. Our year is marked by a cycle of traditional ceremonial activities; the most sacred and perhaps the most recognized is the annual Sha'lak'o event.

While the Pueblo of Zuni may offer the discerning visitor many rich experiences that draw from our deep cultural heritage, our special history, our exquisite arts, and awesome scenic beauty, we like the rest of Indian Country suffer from the same high poverty rates among our families. Our young people drop out of school at much higher rates than non-Native youth. And, our community is ravaged by drug and alcohol use and the ills that go along with it at much higher rates than the general population.

These modern experiences of Native people reflect ongoing social and economic hardships due to a legacy of dispossession, attempted subjugation, and economic deprivation over centuries. It is these hardships that have lead to a successful resurgence of tribal sovereignty and self-determination in remedying the challenges that have been forced upon Native peoples. But Washington's recent budget



tightening and economic austerity (sequester, etc.) make it much more difficult. After all, leaders throughout Indian Country seek the same outcomes as other state and national leaders: to protect the health, safety, and prosperity of the people we serve. It is my hope that Congress will do what is right by American Indians in the upcoming appropriations process and fund vital programs at appropriate levels. Adequate and sometimes increased funding to meet the educational needs of Indian youth; provide adequate health care via the Indian Health Service; ensure responsible resource development for the future; provide safe and secure tribal communities; and supply the long-term investments in tribal public infrastructure and services required to ensure every American Indian enjoys a decent quality of life and has an opportunity to succeed.

I would like to address the specific funding bill this Committee has jurisdiction over, the Labor, HHS, Education appropriations bill for FY 2016, and highlight some of the areas of importance to the Pueblo of Zuni. The Pueblo of Zuni supports:

#### **Education**

- \$5 million for State-Tribal Education Partnership Program (STEP)
- \$5 million for Indian Education Language Immersion Grants
- \$2 billion for Title VIII funding, NCLB (Impact Aid Funding)
- \$5 million for Tribal Education Departments (Dept. of Education)
- \$30 million Title III-A grants under the HEA for Tribal Colleges and Universities
- Full funding for Indian Head Start

#### **Health & Human Services**

- \$1 million for On the T.R.A.I.L. to Diabetes Prevention program
- \$75 million Promoting Safe and Stable Families (discretionary)
- \$60 million for Community-Based Child Abuse Prevention
- \$280 million for Child Welfare Services (tribal allocation)
- \$6 million for SAMHSA, Children and Families Programs

- \$40.5 million for SAMHSA Garrett Lee Smith Grants/Tribal Youth Suicide Prevention
- \$2.94 million for SAMHSA American Indian Suicide Prevention
- \$117 million for Children's Mental Health Services Program
- \$30 million for Older Americans Act
- \$8.3 million for Older Americans Act, Native American Caregiver Support Program

**Labor**

- \$83.5 million to restore funding to YouthBuild Program
- \$65 million to Employment & Training Admin., Indian & Native American Training
- \$125,000 for Native American Employment and Training Council

These funding levels as well as other increases in funding for important programs across Indian Country are vital to live up to the trust responsibility the United States government has to Indian Country. I am confident that this Congress will work in a way that is good for tribes and allow tribes to make progress on key issues such as energy, trust modernization, tribal infrastructure, housing, telecommunications, economic development, labor and tax reform.

Ela'kwa. Thank you.

**RAILROAD RETIREMENT BOARD  
FISCAL YEAR 2016 BUDGET REQUEST  
Statement for the Record, March 16, 2015**

**HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES**

**Michael S. Schwartz, Chairman of the Board  
Walter A. Barrows, Labor Member of the Board  
Steven J. Anthony, Management Member of the Board**

Mr. Chairman and Members of the Committee:

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2016 budget request of \$119,918,000 for our retirement, unemployment and other programs.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. The RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (P.L. 111-5) and extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (P.L. 111-92), the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (P.L. 111-312), the Temporary Payroll Tax Cut Continuation Act of 2011 (P.L. 112-78), the Middle Class Tax Relief and Job Creation Act of 2012 (P.L. 112-96) and the American Taxpayer Relief Act of 2012 (P.L. 112-240).

During fiscal year 2014, the RRB paid \$12 billion, net of recoveries, in retirement/survivor benefits to about 562,000 beneficiaries. We also paid \$86 million in net

unemployment/sickness insurance benefits to about 25,000 claimants. Temporary extended unemployment benefits paid were \$0.8 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.5 billion to about 111,000 beneficiaries.

### **PROPOSED FUNDING FOR AGENCY ADMINISTRATION**

The President's proposed budget would provide \$119,918,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2016. The proposed budget would also provide \$7,980,000 for information technology (IT) investments for automation and modernization of our legacy benefit processing systems. In addition, to discretionary funding, agency seeks \$3.3M in mandatory funding to enhance program integrity processes supporting benefit programs.

### **AGENCY STAFFING**

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 58 percent of our employees have 20 or more years of service, and over 31 percent of our current workforce will be eligible for retirement by fiscal year 2016. As we continue to modernize our information technology infrastructure to automate and convert manual workloads, our agency will also improve training delivery and reporting within our workforce. In fiscal year 2016, we continue to implement a Learning Management System that will provide a comprehensive functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs. This will allow the agency to improve all aspects involved in the learning process to meet our human capital needs as we experience a high rate of change in personnel. Furthermore, we complement this initiative by implementing an executive training program to

prepare and mentor future agency leaders that are ready to replace a significant number of senior leaders within the agency that are eligible to retire.

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management. Also, our budget request includes a legislative proposal to clarify the authority of the Railroad Retirement Board to hire attorneys through competitive civil service.

### **INFORMATION TECHNOLOGY IMPROVEMENTS**

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. In fiscal year 2016, IT funding is targeted toward investments in system modernization and network operation improvements. Key projects include system modernization resource needs for \$6,486,000 in mainframe applications re-engineering, \$1,435,000 for network operations to implement a virtual desktop infrastructure, and \$10,000 to implement the mandatory HSPD-12 Logical Access Controls in our enterprise applications. The agency is in critical need of migrating over 12 million lines of code in COBOL that support 4,200 custom programs included in 200 major applications that serve as the framework for our legacy benefit systems/processes. We have developed a solution based on a proof of concept assessment that will migrate the agency to a flexible architecture with open standards, that transition from batch processing to interactive transactional processing. This solution will

minimize the significant risks in loss of personnel nearing or at retirement age with skills needed to maintain the legacy benefit processing systems. The RRB will be equipped with modern tools and technology to run more efficiently with simplified logic that is easy to understand and document. With the implementation of the virtual desktop infrastructure, these enhanced applications will be available for use on any desktop, tablet, or smart phone. Desktops are virtual, hosted and centrally managed giving end-users a secure and full personal computer experience wherever they are, thereby providing a rich telework experience. Furthermore, these solutions will produce a return on investment to the taxpayer in savings from a decrease in full time equivalents through attrition once system changes are implemented.

### **OTHER REQUESTED FUNDING**

The President's proposed budget includes \$29 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$580,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits." In addition, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

### **NEW FUNDING SOURCE**

The FY 2016 President's Budget also provides \$3,300,000 in mandatory funding for the RRB's program integrity activities. The funds will be used to implement an aggressive program focused on efforts to deter and detect disability fraud and minimize improper payments. The objective of the request is in line with extensive review of current operations and recommendations from the General Accounting Office and RRB's Office of Inspector General. The funds will be no-year funds to provide the RRB with the flexibility to hire and train staff,

train personnel, and conduct increased medical exams and reviews to support the processing of additional program integrity work.

### **FINANCIAL STATUS OF THE TRUST FUNDS**

**Railroad Retirement Accounts** – The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2014, was approximately \$26.1 billion, an increase of almost \$1.1 billion from the previous year. Through January 2015, the Trust had transferred approximately \$17.1 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

The RRB's latest annual report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in June 2014. The overall conclusion is, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 25 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism will automatically increase or decrease tax rates in response to changes in fund balance. Even under a pessimistic employment assumption, this mechanism is expected to prevent cash flow problems for at least 25 years.

**Railroad Unemployment Insurance Account** – The RRB's latest annual report required by Section 7105 of the Technical and Miscellaneous Revenue Act of 1988 was issued in June

2014. The report indicated that even as maximum daily benefit rates rose approximately 41 percent (from \$68 to \$96) from 2013 to 2024, experience-based contribution rates are expected to keep the unemployment insurance system solvent.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

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Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.



Donna J. Dorgan  
155 Union Avenue  
Rutherford, NJ 07070

March 17, 2015

House Committee on Appropriations  
Labor, Health & Human Services, Education & Related Agencies  
The Capitol  
Washington, DC 20510  
VIA EMAIL TO LH.Approp@mail.house.gov

Written Testimony on Appropriations  
U.S. Department of Labor  
Employee Benefit Security Administration  
Misfeasance

Dear Congressmen:

Thank you for the opportunity to address your Committee.

Currently, the Department of Labor does not account for all the money and time spent defending Senior Executive Service managers and senior management officials who engage in discrimination and other inappropriate activities.

The DOL paid out \$820,000 to settle the Whitmore whistleblower retaliation case. Whitmore worked for OSHA and OSHA is charged with protecting whistleblowers. The \$820,000 does not account for the hundreds of hours spent by Department of Labor and Department of Justice employees trying to justify and defend the Department.

The situation is more egregious in the Employee Benefit Security Administration. For example, the DOL paid out \$1.5 million to settle three discrimination lawsuits to former EBSA employees Janet Schmidt, Ekatrina

Uzylan and Karin Weng. The DOL and DOJ expended hundreds of hours defending management through a scorched earth policy of litigation. Meanwhile the discriminating officials continued to work for the Department, receive bonuses and promotions. The same officials were involved in all three cases. These are but a few examples.

The problems are not limited to discrimination. For example, one EBSA manager viewed pornography on the government computer. When an employee complained, she was transferred, not the manager. It is analogous to the response of the Catholic Church to priest sex abuse.

Another SES manager, Jonathan Kay, has served on the board of the Working Theater while serving as the Regional Director of the New York Regional Office of EBSA. At the same time, his wife, Patricia Rodenhause-Kay, was the Regional Solicitor of Labor in New York.

Mr. and Mrs. Kay engaged in fundraising activities and made donations to the Working Theater. Neither he nor his wife recused themselves from Department of Labor investigations or cases involving board members, their organizations or donors to the Working Theater. Many of the members were associated with Taft-Hartley benefit plans and labor unions.

Since EEO payments and litigation costs are not allocated to specific agencies, they do not account for these funds; it is buried in the budget.

It is respectfully submitted that the DOL account for the all funds, including hours and time spent by employees, that it expends defending managers who

engage in inappropriate activities. Managers who are found to have committed the acts, should be terminated, not promoted.

Respectfully yours,

*Donna Dorgan*

Donna Dorgan



**AMERICAN  
SOCIETY FOR  
MICROBIOLOGY**

*Public and Scientific Affairs Board*

Statement of the American Society for Microbiology  
Submitted to the House Committee on Appropriations, Subcommittee on Labor, Health  
and Human Services, Education and Related Agencies on the Fiscal Year 2016  
Appropriation for the National Institutes of Health

March 20, 2015

The American Society for Microbiology (ASM) welcomes the FY 2016 budget request of \$31.3 billion for the National Institutes of Health (NIH) as a first step to increase NIH funding which has been flat since 2003, with a loss of 25 percent in purchasing power. Much of the proposed increased funding would be allocated to addressing specific public health issues that require biomedical expertise and research capabilities, including antimicrobial resistance, precision medicine and the human brain initiative.

In view of the ongoing and emerging health problems confronting the Nation and other countries worldwide, and the unprecedented scientific opportunities on the horizon, we recommend that the budget for NIH be increased to at least \$32 billion in FY 2016. This level of funding would enable NIH to take advantage of the many undifferentiated research project grants that lead to scientific discoveries and contribute to medical innovation. There is an urgent need to increase the NIH budget in view of the decade long attrition in federal funding for biomedical research and the real danger of losing significant numbers of the current and next generation of scientists in the United States. We look forward to working with Congress to enhance NIH's ability to support cutting edge research and training of the scientific workforce.

### **Investing in Biomedical Research and Spurring Innovation in Science**

For over a century, NIH funding has led to new knowledge and advances in medicine. Each year, NIH distributes much of its budget extramurally through more than 50,000 competitive grants, supporting 300,000 plus researchers at more than 2,500 universities, medical schools and other institutions. Intramural programs employ another 6,000 scientists at NIH's own laboratories.

NIH is the Nation's leader in funding biomedical research. Its 27 institutes and centers support studies focused on particular diseases and conditions or on targeted research areas. Last year, NIH reported funding for 235 research areas, conditions and disease categories. Sixty percent of the FY 2016 NIH budget will be distributed extramurally as research project grants and 19 percent through R&D contracts. Intramural research at NIH's own laboratories accounts for another 12 percent of the proposed funding.

The ASM stresses the importance of sustaining adequate NIH funding for long term research efforts. Rising biomedical R&D price indices and flat budgets over the last

decade have undercut NIH spending capabilities. This erosion in federal support has had noticeable negative impacts on biomedical research in the United States.

A clear example is the shrinking number of submitted NIH grant proposals that are successfully funded: From 1 in 3 for all types of grants at the start of the 21<sup>st</sup> century to 1 in 5 by 2014. Decreasing success rates in part reflect rising numbers of submitted requests, but more importantly they are evidence of missed scientific opportunities. In 2014, NIH reviewed more than 51,000 applications for research projects grants (RPGs), selecting 9,241 for funding (an 18 percent success rate, slightly above 16.8 percent the previous year). The Administration's FY 2016 budget would help boost the number of new and competing research grants by approximately 1,200.

The United States has been steadily reducing its biomedical R&D spending while other countries are accelerating their investments. During 2007-2012, the US share of global expenditures slipped from 51 to 45 percent (once 80 percent). The high returns on biomedical R&D investment in improved public health and in science and technology innovation and marketplace economics are well documented. Examples are victories over diseases like smallpox and polio, or the numerous NIH funded recipients of the prestigious Nobel and Lasker awards. Another is federal investment in the Human Genome Project, which has thus far yielded an estimated 178-fold return of nearly \$1 trillion in economic growth.

### **Science Discoveries to Protect Public Health**

Recent outbreaks of Ebola in West Africa and measles in the United States are compelling reminders of the importance of NIH research to addressing health threats. The NIH mission is to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life and reduce illness and disability.

Past federal investments have made NIH the world leader in biomedical research leading to cures, preventives and therapies, whether against old nemeses like tuberculosis and malaria or emerging viral threats like the recent Ebola epidemic or highly virulent influenza strains. ASM supports the funding within the FY 2016 budget for the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of General Medical Sciences (NIGMS), both of which have significantly advanced medical microbiology and related fields like genetics, systems biology and bioinformatics. In the FY 2016 proposal, NIAID would receive a modest 4.5 percent increase over FY 2015 levels, while NIGMS receives 2.6 percent.

NIAID funded studies regularly produce new knowledge and products like vaccines, diagnostic tests, therapeutics and other technologies that safeguard human health and stimulate economic development. Over the decades, NIH supported programs have literally changed the discussion surrounding a disease or condition. A striking example is HIV/AIDS. Once an early death sentence, HIV diagnosis has morphed into chronic illness with science based hope of possible cures and vaccines. NIAID efforts have

contributed immeasurably to promising therapies for HIV infected newborns, successes with early anti HIV drug regimens and advances in vaccine development.

Evolving research emphasis centers on other infectious diseases as medical science advances, for example, influenza, which persists as a heavy burden on the US healthcare system. The 2014 seasonal vaccine's inability to provide effective protection against an important virus strain, due to viral genetic drift after the current vaccine was designed is a strong argument for a universal influenza vaccine, an ultimate goal of NIAID vaccine projects. Scientists recently reported discovery of a new class of antibodies that can neutralize a wide range of influenza A viruses, with potential as a broadly effective, long lasting vaccine. Studies are underway on several other NIAID supported universal vaccine candidates.

### **Fighting Antimicrobial Resistant Infections**

The ASM supports global health initiatives, such as the Administration's newly launched National Strategy for Combating Antibiotic Resistant Bacteria. The multi-agency offensive against antimicrobial resistant (AR) pathogens receives targeted funding in the proposed FY 2016 budget, nearly doubling the amount of federal AR support to more than \$1.2 billion. NIH would receive additional funding for its exploration of new drugs, rapid diagnostics, and biological mechanisms of microbial drug resistance.

Microbial pathogens that acquire resistance to drugs have emerged as one of today's most serious public health challenges. Each year antibiotic resistant infections in this country cause at least two million illnesses and an estimated 23,000 deaths. Associated economic losses total at least \$20 billion annually in excess direct health care and up to \$35 billion in lost productivity. The FY 2016 budget would increase NIAID funding for AR research by \$100 million, to expand its clinical trial capacity to evaluate new antibacterial products, develop a national genome sequence database of AR bacteria and underwrite an original competition to incentivize development of diagnostic devices.

NIAID has battled emerging drug resistance for years, aware that naturally evolving resistance will always occur. In 2014, an updated report on its AR related programs refocused efforts toward specific challenges like cataloguing entire genomes of specific microbes, developing vaccines against resistant *Staphylococcus aureus* and *Neisseria gonorrhoeae*, using healthy bacteria in the human body to combat infection and more. The AR portfolio also includes the search for new broad spectrum therapeutics, more judicious medical and agricultural use of antibiotics, surveillance of spreading AR patterns and research on pathogen biology to determine the mechanisms that lead to resistance.

Over the past year, NIAID solicited new grant proposals from industry to develop rapid diagnostics for five principal causes of resistant infections in hospital settings (*Klebsiella pneumoniae*, *Acinetobacter baumannii*, *Pseudomonas aeruginosa*, *Enterobacter* species, and pathogenic *Escherichia coli*). It began an early stage clinical trial for an oral antibiotic to treat infections of *Clostridium difficile*, an increasingly drug resistant

pathogen responsible for about 250,000 US hospitalizations and at least 14,000 deaths each year.

Relentless appearance of resistant pathogens reinforce how crucial it is to intensify investigations of novel drug classes and supply a more robust drug pipeline. NIAID supported scientists recently reported a new class of antimicrobial drug discovered while screening soil bacteria. Teixobactin, a toxin produced by the newly identified proteobacteria species *Eleftheria terrae*, is the first new antibiotic in more than 25 years. Excitement over the discovery stems from the apparent decreased risk of acquired resistance, as well as the innovative method for growing recalcitrant soil bacteria in the laboratory.

### **Responding to Emerging Infectious Diseases**

When the largest Ebola epidemic in history ignited last year, NIAID accelerated its ongoing research on Ebola treatments and vaccines. That response illuminates the NIH capacity to respond quickly to emerging threats. The ASM applauds NIAID efforts against the Ebola virus and asks Congress to ensure funding for NIH programs that make possible this type of scientific agility against infectious threats.

NIAID supports basic and applied research on Ebola that includes pathogenesis studies using molecular technologies and animal models. Others are characterizing viral transmission patterns using genomic sequencing or examining virus host interactions. NIAID staff deployed to West Africa focused on diagnostics and training local personnel and collected hundreds of Ebola samples for genomic sequencing. NIAID is aggressively seeking therapeutics and vaccines that can stop Ebola's spread, with several candidate drugs in the pipeline and some undergoing early clinical trials. Three Ebola vaccine candidates are currently in various stages of NIH clinical testing, one developed earlier with NIAID funding in partnership with a biotech firm using chimpanzee virus to deliver an Ebola glycoprotein gene that elicits patient immunity.

Other emerging infectious diseases in the NIH portfolio include infections of chikungunya virus and coronavirus MERS-CoV (Middle East Respiratory Syndrome). In May 2014, when the first US case of MERS was confirmed, NIH supported research was well underway. Scientists had identified dozens of compounds that inhibited the MERS virus in the laboratory, as others established a new monkey model to study the severe MERS pneumonia. Last September, NIAID reported that animal studies confirmed dromedary camels as the primary carrier of the virus, which kills about one third of its human victims. Like MERS, there is no specific therapeutic or vaccine for mosquito borne chikungunya virus, first detected in the Western Hemisphere in late 2013. In August 2014, NIAID reported its experimental chikungunya virus vaccine had induced antibodies in an early human clinical trial, just weeks after officials had confirmed the first locally acquired cases in the United States.

The ASM appreciates the opportunity to provide a statement in support of NIH funding and looks forward to working with Congress to provide significant, new funding for biomedical research.



**AMERICAN  
SOCIETY FOR  
MICROBIOLOGY**

*Public and Scientific Affairs Board*

Statement of the American Society for Microbiology  
Submitted to the House Committee on Appropriations Subcommittee on Labor, Health  
and Human Services, Education and Related Agencies on the Fiscal Year 2016  
Appropriation for the Centers for Disease Control and Prevention

March 20, 2015

The American Society for Microbiology (ASM) recommends that Congress approve the Administration's FY 2016 proposed budget for the Centers for Disease Control and Prevention (CDC). The \$7 billion request increases the FY 2015 level by \$110 million to strengthen crucial capabilities of the Nation's principal health protection Agency. The ASM urges Congress to support CDC's unique surveillance and prevention networks, medical R&D activities and rapid response preparedness. The FY 2016 budget will help sustain CDC field operations and laboratories, as well as the Agency's contributions to national and international health initiatives like the Administration's new National Strategy for Combating Antibiotic Resistant Bacteria (CARB) and the international push to eradicate polio.

### **Protecting People from Infectious Diseases**

Microbial pathogens accounted for seven of CDC's ten most important public health challenges in 2014: the Ebola epidemic, antibiotic resistance and healthcare associated infections, a national outbreak of enterovirus D68 (EV-D68) in children, MERS-CoV (Middle East Respiratory Syndrome), the HIV/AIDS pandemic and the global battle against polio.

To combat the infectious diseases that persistently threaten public health, a large portion of the FY 2016 CDC budget (\$2.6 billion) is distributed among three CDC national centers: Immunization and Respiratory Diseases (NCIRD, \$748 million); Emerging and Zoonotic Infectious Diseases (NCEZID, \$699 million) and HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP, \$1.2 billion). The budget also increases funding for several CDC programs that protect against both global and domestic threats: the Strategic National Stockpile, Global Public Health Capacity, Polio Eradication and the Select Agent Program.

The 2015 priority areas targeted by NCEZID illustrate the depth and breadth of the agency's strategy against diverse infectious threats: detect, prevent and control antibiotic resistance in support of the national CARB initiative; continue actions against Ebola in West Africa; eliminate healthcare associated infections (HAIs); update foodborne illness surveillance systems and continue expanding the CDC's Advanced Molecular Detection (AMD) program to compile a large catalog of pathogens' genomic fingerprints.



Last year, NCEZID led more than 37 outbreak investigations and awarded approximately \$134.2 million to health departments across the nation. Nearly 300 NCEZID personnel have been deployed to West Africa since early spring 2014, assisting the fight against Ebola with surveillance, contact tracing, data management, lab testing and health education. NCEZID staff also worked the CDC Emergency Operations Center in Atlanta to provide Ebola logistics, technical expertise, communications and more.

The ASM supports the FY 2016 budget increase of \$264 million for the Antibiotic Resistance Solutions Initiative, CDC's contribution to the new interagency CARB strategy. International and US health agencies are increasingly alarmed by spreading drug resistance among pathogens and by the shortages of new antimicrobials in development. This is a challenge to public health that the US must neither ignore nor fail to overcome. The CDC priority areas include expanded disease tracking with additional local partners, improved drug prescribing in healthcare settings and studies on how antibiotics affect the human microbiome and its ability to protect the body. The Antibiotic Resistance initiative anticipates significant five year reductions in multiple targeted threats, like hospital onset methicillin resistant *Staphylococcus aureus* (MRSA) and carbapenem resistant Enterobacteriaceae (CRE).

The ASM supports the FY 2016 budget request of \$748 million to support CDC immunization programs, including ongoing influenza planning and response. The less than expected protection from this year's seasonal influenza vaccine, due to viral genetic shift post vaccine design, shows the complexities of vaccine R&D and the importance of a consistently excellent CDC vaccine program. As a prevention tool, immunization has been the principal strategy in some of public health's most dramatic successes. In the United States, vaccines were instrumental in stopping once deadly outbreaks of killers like diphtheria, polio and smallpox. CDC currently recommends vaccination to prevent 17 diseases across a lifespan. Staff routinely design vaccination education campaigns, collaborate with local officials, and update immunization protocols.

The current measles outbreak is just the latest reminder of how critical immunizations are to preserving public health, particularly since children under 12 months are too young to be vaccinated and thus highly vulnerable. In 1994, CDC launched the Vaccines for Children program (VFC), responding to that year's measles resurgence causing tens of thousands of cases. A 2014 CDC report estimated that vaccination of children born between 1994 and 2013 ultimately will prevent 322 million illnesses, more than 21 million hospitalizations, and 732,000 deaths, saving nearly \$1.4 trillion in estimated societal costs. CDC also is the scientific lead in global prevention efforts that include vaccines as key cost effective strategies, the global eradication of polio, for example, could save an estimated \$50 billion.

Another CDC surveillance report last August concluded that annual US infant vaccination rates had increased or remained stable for all routinely recommended childhood vaccines, over 90 percent for measles, mumps and rubella (MMR), poliovirus, hepatitis B and varicella (with an increase for rotavirus, from 69 percent in 2012 to 73 percent in 2013). CDC warned, however, that vaccination coverage varied by state and

community, leaving some areas vulnerable. Another 2014 report, released prior to the most recent measles outbreak, noted that US measles cases in January – May were the largest number in the first five months of any year since 1994, nearly all associated with international travel by unvaccinated people.

Results from programs like those against HIV/AIDS and healthcare associated infections point to both progress made and opportunities to improve. A cross section of these statistics exposes CDC's enormous responsibility, for example:

- An estimated 3 million Americans are infected with hepatitis C, plus another 1.4 million with hepatitis B, but at least half do not know they are infected. New hepatitis C infections, which frequently lead to fatal complications, increased by 75 percent between 2010 and 2012, mainly among young people.
- One in 25 hospitalized patients develops healthcare associated infections, too often caused by drug resistant bacteria.
- Each year, about 80,000 refugees and 500,000 immigrants arrive from around the world, while infectious diseases continue to devastate the world's populations.
- Despite vaccine availability, there were nearly 29,000 reported US cases of pertussis (whooping cough) in 2014.
- Seventy percent of the 1.2 million Americans with HIV do not have the virus under control, despite available therapeutics that improve outcomes and greatly reduce the likelihood of transmission (based on 2013 figures).

More than 250 pathogens and toxins are known to cause foodborne illness, accounting for an estimated 48 million US cases each year. In 2014, the agency's annual report on its food safety efforts showed that *Salmonella* infections decreased by about 9 percent in 2013 compared with the previous three years, but campylobacter infections had risen 13 percent since 2008. About 20 million Americans still get sick from norovirus each year. *Salmonella* infections cause another 1.2 million illnesses, with the most deaths of any foodborne bacteria. More disturbing are the multi-drug resistant *Salmonella* types now causing about 100,000 of those cases.

### **Responding to Public Health Threats**

In January, CDC's yearly update on the nation's public health preparedness noted that the agency's Office of Public Health Preparedness and Response processes more than 20,000 calls annually from public health agencies, clinicians and researchers, and the public. Agency experts investigate hundreds of disease reports each year; in the last two years, the agency deployed staff to more than 750 sites to examine health threats. In 2014, outbreak investigations included measles linked to a California amusement park; *Listeria monocytogenes* contaminated cheese, sprouts, and caramel apples; and cases of the intestinal illness cyclosporiasis in at least 20 states, some linked to cilantro. Last July, when the first locally acquired case of chikungunya fever was reported in Florida, CDC had already been actively preparing for its arrival since 2006.

To accommodate this massive workload, CDC partners with US and international health agencies and distributes grants to strengthen community based responses. For example,

CDC funds are allocated to local health departments through the Epidemiology and Laboratory Capacity for Infectious Diseases Cooperative Agreement (\$97.2 million last year to all states, six largest local health departments and US territories) and the Emerging Infections Program (\$37 million to 10 state departments). In November, it added \$2.7 million in personal protective equipment to the Strategic National Stockpile, for rapid deployment response kits ready to send to hospitals with Ebola patients.

To sustain CDC's high quality technical capability, the FY 2016 budget request includes increased support for laboratory safety. In 2014, CDC reviewed its laboratory practices and policies in response to several incidents involving pathogens in Agency laboratories. As a result, changes are underway, including more stringent general enforcement of laboratory safety and quality protocols. Specific recommendations to improve personnel training for FY 2016 include hands on training and expanded distance learning.

### **CDC's Advanced Molecular Detection Program**

Leveraging cutting edge technologies, CDC began its Advanced Molecular Detection (AMD) program with an initial investment in FY 2014. It combines expertise in bioinformatics, epidemiology and genetic sequencing to boost health departments' speed and accuracy in identifying pathogens. AMD projects are underway at CDC facilities, as well as state and local partner laboratories. They are exploring AMD utility for specific diseases or pathogens that include anthrax, brucellosis, bunyaviruses, malaria, filovirus, influenza, gonorrhea, legionellosis, *Listeria*, melioidosis, and meningococcal disease.

AMD projects focused on healthcare associated infections are investigating how specific genes in pathogens change over time, initially for the two high threat bacteria *Clostridium difficile* and carbapenem resistant Enterobacteriaceae. AMD data will also be posted to CDC's online database, MicrobeNet, for use by other researchers and health departments to better identify disease outbreaks, track new and emerging pathogens, and find new ways to prevent illness. Recent examples of AMD enabled research are:

- Identified two new human pathogens from ticks; the Bourbon virus and the Heartland virus. AMD sequencing tools confirmed the two viruses were different.
- Detected enterovirus D68 (EV-D68) in children with severe respiratory illness hospitalized in two states in August 2014, and subsequently recognized the virus causing infections in almost every state; AMD enabled sequencing of the viral genome, contributing to development of a "real time" laboratory test.
- Produced the first whole genomic sequence of Liberian Ebola virus within 72 hours of sample collection from two American patients. The data showed the 2014 virus is 97 percent similar to the Ebola virus that first emerged in 1976.
- Utilized whole genome sequencing to match *Salmonella* in patient samples with that in a peanut butter production plant, quickly initiating a food recall after only four cases of foodborne illness (each case in a different state).

It is impossible to overstate how crucial CDC activities are to protect the health of all Americans and many millions living in other nations. The ASM strongly recommends that Congress increase the CDC's FY 2016 budget.

**Statement of Gregory E. Conrad, Executive Director, Interstate Mining Compact  
Commission Regarding the FY 2016 Budget Request of the Mine Safety and Health  
Administration (MSHA) Within the U.S. Department of Labor**

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**Before the Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies of the House Appropriations Committee**

We are writing in support of the Fiscal Year 2016 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for state assistance grants for safety and health training of our Nation=s miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. MSHA=s budget request for state assistance grants is \$8,441,000. While the proposed amount goes a long way in helping the states provide important safety training and is appreciated by the states, it is approximately the same amount that has been appropriated for state assistance grants by Congress over the past several fiscal years and, as such, does not fully consider inflationary and programmatic increases being experienced by the states. We urge the subcommittee to restore funding to the statutorily authorized level of \$10 million for state assistance grants so that states are able to meet the training needs of miners and to fully and effectively carry out state responsibilities under section 503(a) of the Act. We believe the states can justify the need for funding at the statutorily authorized level.

The Interstate Mining Compact Commission is a multi-state governmental organization that represents the natural resource, environmental protection and mine safety and health interests

of its 26 member states. The states are represented by their Governors who serve as Commissioners.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted state assistance grants as meaning “training grants” only, Section 503 was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mining Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for “Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation’s coal mines.” (H. Conf. Report 91-761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to \$10 million. The training of miners was only one part of the obligation envisioned in Congress.

With respect to the training component of our mine safety programs, IMCC’s member states are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will suffer. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation has been further complicated by new statutory, regulatory and policy requirements that have grown out of the various reports and recommendations attending the Upper Big Branch investigation. We greatly appreciate Congress’ recognition of this fact and this Subcommittee’s strong support for

state assistance grants, especially over the past few years when the Administration sought to eliminate or substantially reduce those moneys.

Our experience over the past 35 years has demonstrated that the states are often in the best position to design and offer mine safety and health training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. MSHA estimates in its budget justification document for Educational Policy and Development (EPD) that the states will train approximately 180,000 miners in FY 2016. The most recent accounting of the number of miners trained by a sampling of the states based on FY 2014 reporting for coal and metal/nonmetal is as follows:

- **Kentucky:** Trained or tested over 17,758.
- **Alaska:** 1,119 miners trained.
- **New Mexico:** 1,942 miners trained.
- **Illinois:** 13,227 miners and contractors trained (including Aggregate Part 46, Coal Mine Accident Prevention, certification and EMT training).
- **Indiana:** 3,247 miners and contractors trained.
- **Oklahoma:** 4,180 miners trained.
- **Pennsylvania:** 6,535 miners trained.
- **Ohio:** 7,000 miners trained.
- **Colorado:** 4,731 miners trained.
- **Arkansas:** 2,573 miners and contractors trained.
- **Nevada:** 2,329 miners trained.
- **North Carolina:** 8,515 miners trained.
- **Maryland:** 452 miners trained (FY 2013).
- **Arizona:** 2,612 miners trained.
- **Virginia:** 4,940 miners trained and 2,422 certifications issued.
- **Mississippi:** 175 miners and contractors trained.

Note that the numbers of miners trained has decreased over the past few years due to the reductions and/or delays in state grant funding. This continues to be a serious challenge for state training programs in FY 2015 with states still awaiting the allocation of grant awards as of March 20, 2015 – six months into the fiscal year. Given MSHA’s reluctance to date to utilize

interim grant allocations during the fiscal year (as other federal agencies do), these delays in authorizing grant allocations are unduly disrupting the states' ability to run effective training programs that rely on certain, consistent and timely funding. Another complicating factor is MSHA's intention to utilize a new formula for distributing grant moneys among the states based on production and employment figures over a five year period of time. While we have yet to see the details of this new approach, the states are concerned about its appropriateness, fairness and overall effectiveness in meeting the respective needs of the states, to say nothing of the certainty and reliability of grant amounts into the future.

As you consider our request to increase MSHA's budget for state training grants, please keep in mind that the states play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) and the Spanish-speaking community in meeting their required training needs.

We also want to bring another matter to your attention because of the implications it may have for mine safety and health programs, as well as related programs under the Surface Mining Control and Reclamation Act of 1977 (SMCRA). Recently, MSHA attempted to assert jurisdiction over an abandoned mine land (AML) project site being reclaimed by the Commonwealth of Pennsylvania as part of its approved AML program under Title IV of SMCRA. Because the project involves the incidental extraction of coal that will be removed from the site and sold (with the proceeds being reinvested in the project), MSHA believes this triggers its jurisdiction under the Mine Act. The project is being undertaken pursuant to a duly promulgated rule by the Office of Surface Mining (OSM) under SMCRA authorizing these

types of “AML enhancement projects”. Since these types of projects began in 1999, MSHA has seldom, if ever, exercised jurisdiction over them.

In an attempt to seek resolution regarding the appropriateness of MSHA jurisdiction over this class of AML projects, the states, through IMCC, met recently with both MSHA and OSM officials to discuss the matter. We learned during the meeting that MSHA is not only seeking to exercise jurisdiction over AML enhancement projects, but over any and all AML projects that involve “reclamation”, arguing that courts have held that “reclamation” of extraction sites is covered under the Mine Act Section 3(h) definition of “mine” because it restores lands, etc. whose condition is caused by (“resulting from”) the work of extraction.

Since the inception of SMCRA in 1977 and the states’ implementation of AML programs beginning in 1979, we are unaware of any circumstances where MSHA has asserted jurisdiction over these types of projects involving coal or noncoal reclamation except in those rare circumstances where an AML contractor inadvertently requested an MSHA ID number. Even in those very limited situations, MSHA has seldom pursued inspection and enforcement once it realized an AML project was underway. We are therefore at a loss for MSHA’s newfound interest in AML projects, which are already regulated by the states, with federal oversight by OSM, and which are generally subject to OSHA jurisdiction. While we are still pursuing this matter with MSHA and OSM, the consequences of a decision rendering these sites subject to MSHA jurisdiction could have debilitating consequences for the AML program under SMCRA and significant budgetary implications for MSHA. We therefore urge the Subcommittee to include language in its report on MSHA’s budget prohibiting the agency from exercising jurisdiction over AML projects under Title IV of SMCRA.



**Testimony of Linda Jaco, Chair****Association of Assistive Technology Act Programs (ATAP)****Before the Subcommittee on Labor, Health and Human Services, Education and Related****Agencies, Committee on Appropriations****Administration on Community Living****United States House of Representatives****March 27, 2015**

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee, I appreciate the opportunity to share the Association of Assistive Technology Act Programs' (ATAP) perspective on federal investments in the Assistive Technology (AT) Act of 2004 (P.L. 108-364). ATAP is a national, member-based organization, comprised of 54 State Assistive Technology Act Programs funded under the Assistive Technology Act (AT Act). The AT Act resides within the Administration on Community Living and receives a total of \$31 million from the federal government, as part of Title II of the Labor, Health and Human Services, and related agencies appropriations bill. This level of funding provided \$25.7 million for the State AT Grant Programs; \$4.3 million for the Protection and Advocacy for Assistive Technology program; and \$1.0 million for technical assistance required under the AT Act's National Activities authority. ATAP was established in 1997 to provide support to State AT Program members to enhance the effectiveness of AT Programs on the state and local level, and promote the national network of AT Programs. ATAP facilitates the coordination of State AT Programs nationally and provides technical assistance and support to its members. ATAP represents the needs and interests of the State AT Programs and is the national voice of the AT Programs.

Funding for the AT Act supports State AT Grant programs that assure people with disabilities have access to and acquisition of the assistive technology services they need to live, work, and attend school in their communities.

State AT Grant Programs exist in every state and territory and support four state-level activities, required by the law: 1) device demonstration; 2) device loan; 3) device reutilization (reuse and exchange); 4) financial loan and other financing programs. State AT Grant programs also are required by law to provide technical assistance and training, and related assistive technology services. State AT Programs play a pivotal role in annually assisting thousands of individuals with disabilities to increase, maintain, or improve their functional capability through the use of appropriate AT. As a result, **ATAP is advocating for full funding of the AT Act (\$38 million) so that State AT Programs can help more individuals benefit from AT and meet the full demand at the state and local level. Full funding would provide the minimum authorized level for each state.**

State AT Grant Programs yield significant savings to consumers and the federal government.

Below is an outline of the return on investment yielded nationally by all four state-level activities:

- **Demonstration Programs** provide opportunities for people to learn about and become familiar with specific types of AT by comparing and contrasting the functions and features of devices through hands on exploration. Instruction is provided by knowledgeable AT professionals in a product neutral environment that does not favor one company or manufacturer. **SAVINGS: 68,070 individuals participated in 39,916 device demonstrations conducted by State AT Programs in FY14. Projecting a modest**

**\$100 savings realized by just half of the total demonstrations conducted results in national savings of approximately \$2 million dollars.**

- Device Loan/Borrowing Programs** allow individuals to borrow – for a limited time period – devices for use at home, school, work etc. Device loans allow borrowers to try out devices in their own environments to determine if a device will meet their needs before a purchase is made. Device loans also can provide loaner AT while a device is being repaired, while a consumer is waiting for funding approvals, or to use for training or professional development purposes. **SAVINGS: 35,243 device loans were made to individuals or agencies with 47,669 devices borrowed from short-term device loan programs operated through State AT Programs in FY14. Using an average savings of \$1,000 per loan with more than one device associated (at least one device was rejected as being a match and a second one was borrowed) results in national savings of well over \$12 million.** Projecting a minimum \$10 per day rental fee for the average loan period of 35 days, results in national savings of almost \$3 million for devices borrowed for accommodation (while a device is repaired or while waiting for funding) or for training since the device did not have to be rented for these purposes.
- Device Reutilization Programs** support the reuse of assistive technology that is no longer needed or used by its original owner. Recipients usually obtain equipment at significantly lower cost or no cost. There are several options for reutilization including reassignment/reuse, device exchange (typically online) and long-term device loans where the borrower keeps the device as long as needed. **SAVINGS: 43,713 recipients acquired 57,745 reutilized devices through State AT Programs in FY14. A total of**

\$25,199,009 was saved by device recipients by purchasing/obtaining reutilized AT instead of new. In addition, close to 70% of the reuse device recipients indicated that they would not have been able to afford the AT if it were not for the reuse services of the State AT Program. The cost of those individuals being unable to work, learn or live in the community without the AT they need would be immeasurable.

- **State Financing Activities** help individuals purchase/obtain AT through a variety of initiatives. Financial loan programs provide consumers with affordable, flexible borrowing options. Other programs provide AT directly to consumers at no cost using dollars from non-AT Act sources or save consumers money when purchasing AT.

SAVINGS: 631 borrowers obtained financial loans totaling \$4,295,953 to buy 639 devices in FY14. These loans were made at an average interest rate of 3.33%. Assuming most standard loans would be at a 7% or higher interest rate, consumers have saved considerable expense through access to this lower rate. 2,385 recipients acquired 2976 devices valued at \$3,183,057 from other state financing programs that directly provide AT using external funding sources. 3,356 recipients acquired 5,557 AT devices with a savings of \$897,808 from other state financing activities, such as cooperative buying programs and device lease programs. The vast majority (84%) of recipients indicated that if the state financing activity they used was not available they would not have been able to purchase/obtain the AT potentially resulting in individuals who are unable to successfully work, learn or live in the community.

**Overall, State AT Grant Programs, based on the fiscal year 2014 federal investment of \$25.7 million, yielded over \$46 million in savings and benefits, leveraged over \$13 million and provided direct services to nearly 700,000 people with disabilities.**

Chairman Cole, your own state of Oklahoma (OK) yields an exceptional return on investment.

The OK State AT Program reutilizes devices purchased by Medicaid that has saved that agency \$378,816 after program costs were recovered by providing 708 pieces of durable medical equipment to 602 Oklahomans. This is the savings from only **ONE** of our state-level activities. This savings is almost equal to the entire allotment Oklahoma receives from the federal government alone.

While it is clear State AT Programs provide cost effective services and supports that improve the lives of people with disabilities and warrant an ongoing federal investment, still there are 11 State AT Act programs that do not receive the minimum grant authorized in the law in 2004 (\$410,000). Due to the tremendous impact programs have on the lives of people with disabilities, and the sincere savings they yield both the government and the consumer, it would be valuable and cost-effective to provide an additional \$7 million to such a successful federal program. This level of funding would bring the AT Act to the full level of funding intended in the statute and benefit thousands more people who need assistive technology.

Thank you for the opportunity to provide testimony to the committee as you make decisions on the fiscal year 2016 budget.



Written Statement for the Record by:

**Sharon P. Pearce, CRNA, MSN**  
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House Appropriations Subcommittee  
 On Labor, Health and Human Services, Education, and Related Agencies  
 2358 B Rayburn House Office Building  
 Washington, DC 20515

March 27, 2015

#### **FY 2016 Appropriations Request Summary**

	<b><u>FY14 Actual</u></b>	<b><u>FY15 Enacted</u></b>	<b><u>AANA FY 16 Request</u></b>
HHS / HRSA / BHPPr Title 8 Advanced Education Nursing, Nurse Anesthetist Traineeship	\$2.94 million	\$2.25 million	\$4 million for nurse anesthesia traineeship
Total for Advanced Education Nursing, from Title 8	\$61.089 million	\$63.581 million	\$66.760 million for advanced education nursing
Title 8 HRSA BHPPr Nursing Education Programs	\$217.50 million	\$231.62 million	\$ 244 million

#### **About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)**

The AANA is the professional association for more than 48,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today,

CRNAs deliver approximately 38 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some states are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons. CRNAs provide high quality anesthesia care to all patient types and case complexities.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report *To Err is Human* found in 2000 that anesthesia was 50 times safer than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a study published in *Health Affairs* led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999-2005, the study compared anesthesia outcomes in 14 states that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 states have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out states alike. (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. *Health Aff.* 2010;29(8):1469-1475.)

CRNAs have provided the majority of anesthesia to our active duty military in combat arenas since World War I and predominate in Veterans hospitals and the U.S. Armed Services through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. Medicare and private payment differences for anesthesia services. GAO-07-463, Washington DC, Jul. 27, 2007. <http://www.gao.gov/products/GAO-07-463>).

### **Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding**

Our profession's chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia traineeships and \$66.760 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of \$244 million. We request that the Report accompanying the FY 2016 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding at least at the fiscal year 2015 level for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request made by The Nursing Community with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this Subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their



healthcare needs, funding the advanced education nursing program at \$66.760 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S. The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings. A 2007 AANA nurse anesthesia workforce study found a 12.6 percent CRNA vacancy rate in hospitals and a 12.5 percent faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2002-2016, the annual number of expected nurse anesthesia educational program graduates increased from 1,362 to 2,559, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 85 to 114. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our 114 nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors -- and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated and licensed registered nurse who has spent a minimum of one year serving in an acute care healthcare practice environment. On average a CRNA applicant obtains three years of experience in a critical care unit prior to

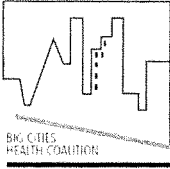
beginning an anesthesia program. They are prepared in nurse anesthesia educational programs located all across the country, including Alabama, Arkansas, California, Connecticut, Idaho, Maryland, Oklahoma, Pennsylvania, Tennessee, and Virginia. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economic\$*, Vol. 28 No. 3, May-June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded federal funding in support of CRNA educational programs.

### **Support for Safe Injection Practices and the Alliance for Injection Safety**

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects involving injection safety. We support the efforts that the CDC's Division of Healthcare Quality and Promotion has taken regarding its injection safety activities, including provider education and awareness, detection, tracking and response.

# # #



**Statement of the Big Cities Health Coalition  
1100 17<sup>th</sup> St. NW, 7<sup>th</sup> Floor, Washington, DC 20036**

**Submitted for the record to the Subcommittee on Labor, Health and Human  
Services and Education, Committee on Appropriations  
United States House of Representatives**

**FY 2016 Appropriations for  
Programs at the Department of Health and Human Services**

ATLANTA (FULTON COUNTY)

BALTIMORE CITY

BOSTON

CHICAGO

CLEVELAND

DALLAS (DALLAS COUNTY)

DENVER

DETROIT

HOUSTON

LOS ANGELES COUNTY

MIAMI (MIAMI DADE COUNTY)

NEW YORK CITY

PHILADELPHIA

PHOENIX (MARICOPA COUNTY)

COUNTY OF SAN DIEGO

SAN ANTONIO

SAN FRANCISCO

SAN JOSE (SANTA CLARA COUNTY)

SEATTLE (KING COUNTY)

DISTRICT OF COLUMBIA

**Contact:** *Vicky Bass, Big Cities Health Coalition Government Affairs Specialist*  
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The Big Cities Health Coalition (BCHC) is comprised of the health officials leading twenty-six of the nation's largest metropolitan public health departments in the country's most urban areas. Together our members promote and protect the health of approximately one in six Americans.

On behalf of local health departments, BCHC submits the following requests:

**Public Health Emergency Preparedness:** Recently, health departments have responded to the threat of infectious diseases like Ebola and measles and more severe and frequent weather events causing natural disasters. Emergency federal funding to respond to the unexpected threat of Ebola is much appreciated. However, sustained funding to support local preparedness and response capacity is needed to make sure every community is ready for any disaster it may confront.

A critical component of protecting and securing our nation's public health and our nation's security is having state, local, and territorial agencies prepared to prevent, detect, respond to, and rapidly recover from a variety of threats. Federal public health emergency preparedness funding is provided to large metropolitan health department either directly (New York City Los Angeles County, Chicago, Washington DC) or through state health departments by the Centers for Disease Control and Prevention (CDC) and the Assistant Secretary for Preparedness and Response (ASPR).



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These funds are critical to preparing for and responding to public health emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies. Urban areas are particularly vulnerable to such threats due to their population size.

***CDC Public Health Emergency Preparedness:*** The BCHC urges you to provide \$675 million to the Public Health Emergency Preparedness (PHEP) grant program at CDC, rejecting the President's proposed \$9.8 million cut to Other State and Local Capacity. PHEP grants have been cut more than 29% over the last decade (FY2005-FY20015) with more than 55% of local health departments relying solely on federal funding for emergency preparedness activities. PHEP protects communities by strengthening state and local public health department capacity to effectively respond to public health emergencies. State and local health departments work with the federal government, law enforcement, emergency management, health care, business, education, and faith-based groups to plan, train, and exercise for emergencies so that when disaster strikes, communities are prepared. PHEP was critical to the state and local response to Ebola.

***ASPR Hospital Preparedness Program:*** BCHC urges you to fund the Hospital Preparedness Program (HPP) at \$300 million. HPP provides funding to states and the four directly funded cities that in turn fund local health departments, healthcare facilities, and other partners to build capabilities and capacities that strengthen the preparedness, response, recovery, and resilience of the public health and healthcare system. HPP supports health department preparedness coordinators to organize coalitions of public health and healthcare providers to plan and prepare for public health emergencies, including medical surge following terrorist attacks, mass casualty incidents, an influenza pandemic or other infectious disease outbreak. In FY2014, HPP was cut

by \$100 million marking a loss of over 50% in funding over a decade (FY2005-2015). The recent emergence of Ebola in the U.S. showed the need for strong public health and hospital partnerships supported through HPP.

HPP-funded planning, preparation and capacity-building was critical during the 2013 response to the Boston Marathon Bombings, during which the Boston Office of Public Health Preparedness, a part of the Boston Public Health Commission (their local health department), served as a hub for information sharing, care coordination and volunteer management. HPP funding laid the groundwork that made it possible for Boston's six level-one trauma centers to receive the surge of 164 patients immediately following the bombing and also aided in the ongoing coordination of care and services for these patients, their families and other survivors of the Boston attack.

***Collaborative Partnerships with States:*** States and major metropolitan areas need to work in collaborative partnerships. BCHC believes that in order to do so an understanding of the extent to which federal resources are getting to the local level is needed. Therefore we urge inclusion of report language directing CDC to provide information on how much of the state PHEP grants are being allocated to local health departments by the state and on what basis or formula each state is using to make such allocations, including the method through which states reach statutorily-required concurrence with local health departments. Similarly, we urge you to request information from ASPR on how state HPP funding is distributed at the local level, including how much is being allocated to local health departments by each state and on what basis or formula each state is using to make such allocations. This information should be publicly available.

**Immunization:** BCHC urges you to fund the Section 317 Immunization Program at \$650 million, rejecting the President's \$50 million cut. BCHC supports the \$8 million included in the President's budget to build health department capacity for billing. The 317 Immunization

Program funds 50 states, six large cities (Chicago, Houston, New York City, Philadelphia, San Antonio and Washington, D.C.) and eight territories for vaccine purchase for at-need populations and immunization program operations, including education and outreach on the importance of vaccines, as well as support for implementing billing systems for immunization services at public health clinics to sustain high levels of vaccine coverage. Immunizations continue to be one of the most cost-effective public health interventions. According to CDC, childhood vaccines saved 42,000 lives and prevented 20 million cases of disease with an estimated \$10.20 in savings for every \$1 invested.

Efforts to promote vaccination are perhaps needed more now than ever despite extraordinary public health successes. The United States experienced a record number of measles cases during 2014, with 644 cases from 27 states, according to the Centers for Disease Control and Prevention (CDC). From January 1 to March 13, 2015 alone, 176 people from 17 states and the District of Columbia were reported to have measles. The rapid spread of this disease illustrates the need for a strong public health immunization infrastructure to prevent disease in both children and adults.

**Preventing Opioid Abuse:** BCHC urges your support for \$133 million for preventing opioid abuse as included in the President's budget requests. Of the total, \$48 million should be directed to CDC for state-level overdose prevention, including improvements in prescription drug monitoring programs, and \$5.6 million in new funding to address heroin-related overdose deaths through collection of real-time hospital emergency data and better mortality data. The Substance Abuse and Mental Health Services Administration should receive \$12 million for a new 10-state grant program aiming to reduce opioid-overdose deaths through purchase of naloxone and training of first responders to use it and \$10 million for state prevention efforts and \$13 million to support medication-assisted addiction treatment.

Metropolitan health departments are on the front lines of responding to the opioid epidemic identifying “hot spots” through surveillance and coordinating community partners to raise awareness and creating opportunities for prevention of opioid abuse and overdose. Additionally, metropolitan health departments have and continue to combat the devastating impact of opioid abuse, misuse and overdose through coordination of prescription drug give-back programs, research-driven educational programs, and partnerships with law enforcement. With the leadership of our metropolitan health departments, many local communities have taken strides to make sure that Naloxone should be made available to all first responders to counter the effect of heroin and opioid overdoses.

**Antibiotic Resistance Initiative:** BHC urges your support for \$264 million for CDC’s Antibiotic Resistance Initiative to implement CDC’s activities under the National Strategy for Combating Antibiotic-Resistant Bacteria (CARB). This funding would establish antibiotic resistance prevention programs in 50 states and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria. Medically acquired “super bug” infections have affected several big city health systems this year and more must be done to address the cause and spread of antibiotic-resistance bacteria so that additional infections can be prevented through sound science and appropriate regulation.

As the Subcommittee drafts the FY2016 Labor-HHS-Education Appropriations bill, BCHC urges consideration of these recommendations for programs critical to protecting the public’s health.

**STATEMENT BY AMERICAN HEART ASSOCIATION  
ELLIOTT ANTMAN, M.D., PRESIDENT  
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**FY 2016 LABOR-HHS-EDUCATION APPROPRIATIONS: NIH, CDC, HRSA**

Remarkable strides have been made in the prevention and treatment of cardiovascular disease (CVD) and stroke. However, we must face the hard truth. There is still no cure for America's No. 1 and most costly killer. CVD costs nearly \$1 billion a day. Stroke is our No. 5 killer and second leading cause of dementia.

Today, nearly 86 million U.S. adults suffer from some form of CVD and those grim statistics will only get worse. It is projected that by the year 2030, nearly 44% of U.S. adults will live with CVD at a cost exceeding \$1 trillion annually. Yet inexplicably, CVD research, prevention, and treatment remain disproportionately underfunded with no sustained and stable funding from the National Institutes of Health. Therefore, we emphasize that robust NIH-funded research is vital for a continuing and effective campaign against these deadly and debilitating diseases.

The American Heart Association recognizes the challenges our nation and Congress face to reduce the budget deficit. However, sequestration is not, and never is the answer. These cuts put at grave risk the health of tens of millions of CVD sufferers, stifle economic growth, and jeopardize our global leadership in medical research. We therefore challenge Congress to appropriate stable and sustained funding for CVD research, prevention, and treatment. Moreover, during the upcoming debate on funding, Congress should recognize that NIH-funded research has a proven return on investment. It drives economic growth, including good, high-paying jobs,



stimulates innovation, and maintains America's time-honored leadership in medical research—something that is now under threat with the current budget constraints on the NIH.

## **FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION**

It comes down to this. Research that could move us closer to a cure for cardiovascular disease and stroke goes unfunded. Congress must capitalize on 50 years of progress or our nation will pay more in lives lost and health care costs. Our recommendations tackle these issues in a fiscally responsible way.

### **Capitalize on Investment for the National Institutes of Health (NIH)**

Robust NIH-funded research helps prevent and cure disease, transforms patient care, stimulates economic growth, fosters innovation, and maintains U.S. leadership in pharmaceuticals and biotechnology. NIH is the world's leader of basic research—the foundation for all medical advances—and an essential Federal government function that the private sector cannot ever replace. But, our country's competitive edge in scientific research has been eroded in recent years by scarce funding.

In addition to improving health, NIH generates a solid return on investment. In FY 2012, NIH supported 400,000 U.S. jobs and created about \$60 billion in new economic activity. Every \$1 in NIH funding created \$2 in economic activity in 2007. Yet, due to scarce resources over the past decade, NIH lost more than 20% of its purchasing power. Sadly, this decline occurred at a time of unprecedented scientific opportunity as other countries wisely increased investment in science—some by double digits. These cuts have disheartened early U.S. career investigators who may decide against pursuing a career in research unless Congress takes action.

***American Heart Association Advocates:*** We urge Congress to appropriate \$33 billion for NIH to begin to restore its purchasing power, and advance cardiovascular disease research.

**Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment**

NIH research plays a pivotal role in reducing CVD death rates. Today, scientists are close to discoveries that could result in revolutionary treatments and even cures. In addition to saving lives, NIH studies are economical. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progestin trial generated a total economic return of \$140 for every \$1 invested in the trial and led to 76,000 fewer cases of cardiovascular disease. The first NIH tPA drug trial led to a 10-year net \$6.47 billion reduction in stroke care costs.

**Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)**

Much of the decline in cardiovascular disease death rates is a result of NHLBI-funded research. However, this begs the question, "Why has NHLBI extramural heart research fallen 17% in constant dollars since 2002?" Stable and sustained NHLBI funding remains key to building on investments that have led to major advances. Look at losartan as an alternative treatment for Marfan syndrome; the identification of loss of-function apolipoprotein C3 gene changes as a potential therapy for cutting heart disease risk; the use of nanoparticles to cut atherosclerotic plaque inflammation; and cells from human induced pluripotent stem cells to fix damaged heart tissue. Sustained funding will allow the NHLBI to implement its bold strategic vision.

**Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)**

An estimated 795,000 Americans will suffer a stroke this year and nearly 129,000 will die from one. Many of the 7 million survivors deal with grave physical, mental, and emotional distress. In

addition, stroke costs an estimated \$34 billion in medical expenses and lost productivity each year and a recent study projects that direct costs of stroke will triple between 2010 and 2030.

Stable and sustained NINDS funding is vital to building on stroke advances, including research showing that a stent system removes clots in large blood vessels to stop stroke damage. More resources could also help improve stroke recovery; boost NIH Stroke Trials Network; hasten translation of preclinical animal models into clinical studies; prevent vascular cognitive damage; expedite comparative effectiveness research trials; develop imaging biomarkers; refine clot-busting treatments; achieve robust brain protection; and promote the use of neural interface devices. Additional funding is also needed to support the BRAIN Initiative.

***American Heart Association Advocates:*** We recommend that NHLBI be funded at \$3.3 billion and NINDS at \$1.8 billion.

#### **Increase Funding for the Centers for Disease Control and Prevention (CDC)**

Prevention is the best way to protect us from the physical and fiscal ravages of heart disease and stroke. Yet, proven efforts are not fully executed due to scarce funds. We thank Congress for retaining in P.L. 113-203 the needed boost for the Division for Heart Disease and Stroke Prevention. In addition to funding research and evaluation and developing a surveillance system, the DHDSP directs Sodium Reduction in Communities and the Paul Coverdell National Acute Stroke Registry. DHDSP and the Centers for Medicare and Medicaid Services are promoting the Million Hearts™ initiative aimed at stopping 1 million heart attacks and strokes by 2017. DHDSP runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64. It helps

them from becoming heart disease and stroke statistics through preventive health services, referrals to local health care, and tailored lifestyle plans to foster lasting behavioral change.

***American Heart Association Advocates:*** We join the CDC Coalition in asking for \$7.8 billion for CDC's program level. AHA requests \$130.037 million for the DHDSP to intensify work on the State Public Health Actions and on the State and Local Public Health Actions To Prevent Obesity, Diabetes, Heart Disease, and Stroke; and \$37 million for WISEWOMAN. We ask for \$5 million for Million Hearts™ to better control blood pressure—a “silent killer” of Americans.

#### **Restore Funding for Rural and Community Access to Emergency Devices (AED) Program**

About 90% of cardiac arrest victims die outside of a hospital. Yet, early CPR and use of an AED can more than double survival. Communities with full AED programs have survival rates near 40%. HRSA's Rural and Community AED Program awards competitive grants to states to buy AEDs, tactically place them, and train lay rescuers and first responders in their use. As a result of this program, nearly 800 patients were saved from August 1, 2009 to July 31, 2010. But scarce resources allow only 19% of approved applicants in 6 states to receive funds in FY 2014.

***American Heart Association Advocates:*** We advocate for an \$8.927 million appropriation for PHS Act sections 413 and 313, returning the program to FY 2005 levels with 47 funded states.

### **CONCLUSION**

Cardiovascular disease, including stroke, still inflict a staggering physical and economic toll on the American people. Our recommendations for NIH, CDC, and HRSA will save lives and reduce health care costs. We respectfully ask the Committee to endorse our recommendations that are a wise investment for our great nation and the well-being of this and future generations.



*Submitted for the Record to the House Appropriations Subcommittee  
on  
Labor, Health and Human Services, Education, and Related Agencies  
March 27, 2015*

William Lang, Senior Policy Advisor  
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The American Association of Colleges of Pharmacy (AACCP) is pleased to submit this statement for the record regarding FY2016 funding. The 134 accredited pharmacy schools are engaged in a wide range of programs funded by the agencies of the Department of Health and Human Services (HHS) and the Department of Education. Recognizing the difficult task of balancing needs and expectations with fiscal responsibility, AACCP respectfully requests that the following agencies and programs be funded appropriately as you undertake your deliberations:

- Health Resources and Services Administration (HRSA) - \$7.48 billion
  - Title VII & VIII - \$524 million
- Agency for Healthcare Research and Quality (AHRQ) - \$375 million
- Centers for Disease Control and Prevention (CDC) – \$7.8 billion
  - National Center for Health Statistics (NCHS) - \$172 million
- National Institutes of Health (NIH) - \$32 billion

In addition, AACCP respectfully requests that the Fund for the Improvement of Post-Secondary Education (FIPSE) be funded at \$100 million and that the maximum Pell grant appropriated discretionally be maintained at \$4860.

**US DEPARTMENT OF HEALTH AND HUMAN SERVICES - Health Resources and Services Administration (HRSA) AACCP supports the Friends of HRSA recommendation of \$7.48 billion for HRSA in FY16.** Dr Bryan Love from the South Carolina College of Pharmacy received \$94.900

from HRSA to research the connection between antibiotics and food allergies in children. Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research on rural health delivery via telemedicine. Schools of pharmacy are supported by HRSA to operate some of the 57 **Poison Control Centers**. AACP supports the **Bureau of Health Workforce (BHW)** and the **National Center for Health Workforce Analysis**. Through the Pharmacy Workforce Center, AACP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. **AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$524 million for Title VII and VIII programs in FY16.** AACP member institutions are active participants in BHW programs. Schools of pharmacy participate in Title VII programs, including Geriatric Education Centers and Area Health Education Centers (AHEC). These community-based, interprofessional programs are **essential** for supporting innovative educational models addressing national issues at the local level through team-based, patient-centered care. They serve as valuable experiential education sites for student pharmacists and other health professions students. Pharmacy schools are eligible to participate in the **Centers of Excellence** program and the **Scholarships for Disadvantaged Students** program, to increase the number of underserved individuals attending health professions schools and increase minority health workforce representation. Colleges of pharmacy, including Xavier University of Louisiana, develop and maintain centers of excellence in diversity supported by HRSA Centers of Excellence grants.

**Agency for Healthcare Research and Quality (AHRQ) - AACP supports the Friends of AHRQ recommendation of \$375 million in budget authority for AHRQ programs in FY16.** Pharmacy

faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Dr. C. Daniel Mullins, at the University of Maryland, received \$995,295 to study patient-centered involvement in evaluating effectiveness of treatment. **Centers for Disease Control and Prevention (CDC)** - AACP supports the CDC Coalition recommendation of \$7.8 billion for CDC core programs in FY16 and the Friends of NCHS recommendation of \$172 million for the **National Center for Health Statistics**. Information from the NCHS is essential for faculty engaged in health services research and for the professional education of the pharmacist. The educational outcomes for pharmacy graduates include those related to public health. The opportunity for pharmacists to identify potential public health threats through regular interaction with patients provides public health agencies with on-the-ground epidemiologists providing risk identification measures when patients seek medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research and activities including delivery of immunizations, integration of pharmacogenetics in the pharmacy curriculum, inclusion of pharmacists in emergency preparedness, and the Million Hearts campaign. Dr. Leigh Ann Ross and Dr. Lauren S. Bloodworth, at the University of Mississippi received \$406,978 from the CDC and the Mississippi State Department of Health for the Pharmacy Cardiovascular Risk Reduction Project.

**National Institutes of Health** - AACP supports the Adhoc Group for Medical Research recommendation of at least \$32 billion for NIH funding in FY16. Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the full spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In fiscal year 2013, pharmacy

faculty researchers received nearly \$311 million in grant support from the NIH. Academic pharmacy sustains a strong commitment to increasing the number of biomedical researchers. Dr. Gunda George, at the University of Minnesota, received \$8,300,000 to design, synthesize and evaluate non-hormonal contraceptives for men and women. Dr. Eli Chapman and Dr. Donna Zhang, at the University of Arizona received \$1,700,000 to study, "Stress response, p97 and Nrf2 in arsenic-mediated toxicity."

**US DEPARTMENT OF EDUCATION** - The Department of Education supports the education of healthcare professionals by assuring access to education through student financial aid programs, educational research allows faculty to determine improvements in educational approaches; and the oversight of higher education through the approval of accrediting agencies. **AACP supports the Student Aid Alliance's recommendations to maintain the discretionary contribution to the \$4860 maximum Pell grant.** Admission to a pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are essential to assuring students have access to undergraduate, professional and graduate degree programs. **AACP recommends a funding level of at least \$100 million for the Fund for the Improvement of Post-Secondary Education (FIPSE)** as this is the only federal program that supports the development and evaluation of higher education programs that can lead to improvements in higher education quality.



**Deborah A. P. Hersman, President & CEO, National Safety Council**

Chairman Cole, Ranking Member DeLauro, and Members of the subcommittee, thank you for the opportunity to submit testimony regarding the National Safety Council appropriations priorities. My name is Deborah Hersman, and I am President and CEO of the National Safety Council. We are a more than 100 year-old Congressionally chartered nonprofit safety organization dedicated to saving lives by preventing injuries and deaths at work, in homes and communities, and on the roads through leadership, research, education, and advocacy. Our more than 13,000 member companies represent nearly 8 million employees at more than 53,000 U.S. worksites. Today I am seeking support for \$592.1 million for the Occupational Safety and Health Administration (OSHA) and \$334.863 million for the National Institute for Occupational Safety and Health (NIOSH), two agencies whose work is vital to protecting the health and safety of America's workers. I am also seeking support for increased funding to fight the continuing prescription opioid abuse epidemic, including \$68 million for the Centers for Disease Control and Prevention (CDC) and \$210.9 million for the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Substance Abuse Prevention.

**Occupational Safety and Health Administration**

An effective and efficient OSHA is critical to preventing workplace fatalities, injuries and illnesses. NSC supports balanced, stable funding for OSHA that adequately funds all the agency's key functions, including compliance assistance and support to companies striving for safety excellence, the timely promulgation of regulations to protect America's workers, enforcement actions against companies that fail to comply with OSHA standards, and whistleblower protection for workers.

The Council supports the top line funding level of \$592.1 million for the agency included in the President's FY 16 budget request, and we strongly encourage the committee to fund the agency at a minimum of this funding level. While the Council is pleased that OSHA rulemaking and enforcement efforts have been restored to pre-sequester funding levels, we continue to have strong concerns about funding constraints placed on the agency's federal compliance assistance efforts, which are presently funded at \$68.4 million, more than 10 percent less than FY 12 enacted levels. The President's proposed funding level of \$73 million would restore most of these funds.

#### National Institute for Occupational Safety and Health

Funding NIOSH at a minimum of the FY 15 program level of \$334.863 million, and preserving the FY 15 level of \$24 million for the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and \$27.5 million for the Education and Research Centers (ERCs), is essential to ensuring that NIOSH can fulfill its mission of saving lives and preventing injuries.

NIOSH's primary responsibility is to conduct research and make recommendations for the prevention of work-related injuries and illnesses. The Council is disheartened to see the President's budget request again target for elimination the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and Education and Research Centers (ERCs).

NIOSH established the AgFF program in 1990 in response to evidence that agricultural workers were suffering higher rates of injury and illness than other U.S. workers. The agriculture, forestry, and fishing, industry fatality rate is more than 8 times that of the all-industry average. Yearly, almost 18,000 workers in this sector are injured seriously enough to require time away

from work.<sup>1</sup> Today, the initiative includes nine regional centers and one national center to address children's farm safety. These centers conduct vital research leading to evidence-based standards that save lives.

NIOSH supports education and research in occupational health through academic degree programs and research opportunities, primarily through 18 university-based ERCs located at leading universities around the country serving all 50 states. The mission of the ERCs is to reduce work-related injuries and illnesses in the U.S. by performing prevention research and by educating, through degree programs and continuing education, high-quality professionals who implement programs to improve occupational health and safety and minimize the dangers faced by workers across the country. Currently, the ERCs are responsible for supplying many of the country's OSH graduates who will go on to fill professional roles. With an aging occupational safety and health workforce, and a critical shortage of qualified OSH professionals, ERCs are essential to educating the next generation of professionals.

### **Prescription Drug Overdoses**

Today, fatalities from drug overdose, mainly due either directly or indirectly to opioid pain killers, have become the leading cause of unintentional death. Two of the agencies working to address the prescription drug overdose epidemic are the Centers for Disease Control and Prevention and the Substance Abuse and Mental Health Services Administration.

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<sup>1</sup> U.S. Bureau of Labor Statistics, U.S. Department of Labor. (2013). Table 2. numbers of nonfatal occupational injuries and illnesses by case type and ownership, selected industries, 2012. Retrieved February 12, 2014, from <http://www.bls.gov/news.release/osh.t02.htm>.

### CDC Injury Center

The CDC's Injury Center addresses the need for a coordinated effort to prevent injuries in the United States, and functions as a focal point for the public health approach to preventing injuries. CDC Injury Center activities have focused on two main drivers of the prescription drug overdose problem – high-risk prescribing and high-risk patients. Much of their effort to date has focused on conducting research on the issue, with several peer-reviewed materials recently published.

Funding the Injury Center's prescription drug efforts at the \$68 million funding level included in the President's FY 16 budget request would immeasurably advance the agency's ability to make a significant impact on the epidemic. CDC would use these additional funds to expand the Prescription Drug Overdose Prevention for States program to fund all 50 states and the District of Columbia to create a unified, national approach to the epidemic. These funds would be used for activities such as enhancing prescription drug monitoring programs, implementing guidelines to improve physician prescribing behaviors, and enhancing insurance mechanisms to improve prevention.

### Substance Abuse and Mental Health Services Administration

Lastly, I'd like to discuss funding for the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA's Center for Substance Abuse Prevention (CSAP) is responsible for developing policies, programs, and services to prevent the onset of illegal drug use, prescription drug misuse and abuse, alcohol misuse and abuse, and underage alcohol and tobacco use. The National Safety Council requests that Congress at a minimum fund CSAP at the \$210.9 million funding level requested in the President's FY 16 budget, including \$12 million

for the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths program, to advance the distribution and use of naloxone.

Naloxone treats opioid and heroin overdoses by stopping the respiratory depression caused by too much of these drugs. Available by prescription, it is not a controlled substance and has no demonstrated potential for abuse. Research has shown that administering naloxone is a cost-effective and life-saving treatment, and the use of naloxone has reversed more than 10,000 overdoses.<sup>2</sup>

Funding this new grant program in CSAP will provide for grants to 10 states to purchase naloxone, equip first-responders in high-risk communities, support education on the use of naloxone and provide the necessary materials to assemble overdose kits.<sup>3</sup> In a time of tight budgets at the federal, state and municipal levels, ensuring a dedicated funding stream for these life-saving efforts is critical to driving down the rate of prescription opioid overdose.

Thank you again for the opportunity to submit testimony for the record.

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<sup>2</sup> Wheeler E. MMWR: community-based opioid overdose prevention programs providing naloxone – united states, 2010. 2012. Centers for Disease Control and Prevention.

<sup>3</sup> SAMHSA. FY 16 Congressional Budget Justification

**Donna M. Carmical**  
**Written testimony prepared for the House Subcommittee on**  
**Labor, Health and Human Services, and Education and Related Agencies**  
**Testimony addressing National Institute of Health (NIH) 2016 Budget Request**

Members of the subcommittee thank you for taking the time to consider public testimony regarding the National Institute of Health (NIH) 2016 budget request. NIH has requested a \$1 billion dollar increase for 2016. Public documents indicate that key investments are for Alzheimer's research, Precision Medicine Initiative, Antimicrobial Resistance, AIDS, the Brain initiative, etc. Changes from the 2015 enacted budget to the 2016 President's Budget request indicates this billion dollar investment provides on average a 3% increase for every institute/center across NIH. Although childhood cancer research is the #1 disease related killer of children in the U.S. it is rarely mentioned in the NIH budget and not a line item in the National Cancer Institute (NCI) budget.

My name is Donna Carmical, I live in Fredericksburg, VA. On March 9, 2010 our lives were forever changed when our grandson, Declan Carmical, was diagnosed with a rare form of pediatric cancer called AT/RT (atypical teratoid/rhabdoid tumor). Hearing that your child/grandchild has cancer is devastating but hearing Doctor's say that there are no treatments, no cures, no hope is incomprehensible. Doctor's advised that we should take our beautiful Declan home, make him comfortable, and that he would be dead in a few weeks. Our sweet Declan lost his battle 8 days before his first birthday. This testimony is not about Declan, but because of him and what we learned about the insidious world of pediatric cancer.

What we learned about the treatments kids endure and the statistic no one talks about, that only about 20% of children survive pediatric cancer treatments without significant impact. Each decade we lose approximately 27,000 children to cancer in the U.S., decade after decade, and there is no reason to believe that this will change without significant investment of Federal research funding. Childhood cancer research is an area sadly neglected as budget decisions are

March 25, 2015

Donna M. Carmical  
 Written testimony prepared for the House Subcommittee on  
 Labor, Health and Human Services, and Education and Related Agencies  
 Testimony addressing National Institute of Health (NIH) 2016 Budget Request

made by the National Institute of Health (NIH). NIH continues to lamely defend their lack of investment by saying that research in adult cancers brings benefits to childhood cancers, there are insufficient resources to increase funding levels for childhood cancer research and a myriad of other excuses from the brilliant researchers that make agency budget decisions.

The National Cancer Institute (NCI) says that childhood cancer is rare. They indicate that annually approximately 16,000 kids are diagnosed with pediatric cancer and that childhood cancer is on the rise. The fact that 1 in 285 children will be diagnosed with cancer is not acceptable statistic, especially in terms of deciding that this is an area that doesn't need real investment of research funding. Approximately 1 in 5 children diagnosed with cancer are terminal on diagnosis and 2 out of 3 children suffer life altering impacts as a result of treatments. In the U.S. alone, approximately 2,700 children die each year as a result of pediatric cancer.

According to NCI there are currently 380,000 survivors of childhood cancer in the U.S., they project this number will increase over time. Adult chemotherapy is proven to help cure cancer with many side effects. Adult treatments are approved for children, provided at a lower dose for kids. As StandUp2Cancer reports on their webpage – "While childhood cancer research often yields discoveries that benefit adults with cancer, **the opposite is less common**. Children are not simply smaller versions of adults, and childhood cancers are very different from the cancers that strike adults."

Many children suffer life altering impacts of treatment. If they pass the 5 year survival rate -- they are statistically considered cured; yet, many children suffer long term impacts, secondary cancers, heart problems, infertility, learning disabilities, stunted growth, hearing problems and more. The increase in survivors, burden of disease, growing number of survivors,

**Donna M. Carmical**  
**Written testimony prepared for the House Subcommittee on**  
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**Testimony addressing National Institute of Health (NIH) 2016 Budget Request**

as well as number of deaths each year are a great cost to society in so many ways. An investment in childhood cancer research could deliver big results -- pediatric protocols that might result in cures, less invasive treatments, reduction in life altering impacts, etc. In addition, as some in the medical community have indicated, there is a belief that childhood cancer research has the potential to bring knowledge about adult cancer research.

Childhood cancer is not one disease, there are 16 major types of cancer and over 100 subtypes. Many of these childhood cancers, like DIPG, AT/RT, receive little to no funding for research. NCI indicates that survival rates for a few childhood cancers like acute lymphoblastic leukemia (ALL) have improved dramatically over the past decades, ironically this is due to the investment in research. NIH makes little mention of statistics regarding the deadly childhood cancers where for decades there has been little to no research. There are many other statistics related to childhood cancer; yet, despite compelling statistics, childhood cancer is vastly and consistently underfunded and virtually ignored in terms of Federal research funding.

Ironically many pediatric cancer organizations raising funds for childhood cancer research have been started by families who have lost a child to pediatric cancer. These families are trying to fund research because their eyes have been opened to the lack of childhood cancer research funding and the life changing consequences to society. Families desperately want other kids to have cures denied to their own children. The thing is that even the largest organizations are raising tens of millions of dollars, compared to Federal dollars, the little money that is raised by private organizations means that potential cures are probably decades into the future. Childhood cancer research needs a huge investment, an investment of billions that can only be accomplished by putting our tax dollars to work for kids.

March 25, 2015



**Donna M. Carmical**  
**Written testimony prepared for the House Subcommittee on**  
**Labor, Health and Human Services, and Education and Related Agencies**  
**Testimony addressing National Institute of Health (NIH) 2016 Budget Request**

Following the AIDS pandemonium in the 1980s, Congress provided billions for AIDS research. Dr. Collins has testified that success with HIV/AIDS research “may enable us to envision the first AIDS free generation since the virus emerged more than 30 years ago.” This success would not have been possible without the substantial investment of dollars in AIDS research, an investment of tens of billions of taxpayer dollars over the last few decades. Today 10% of NIH funding, approximately \$3B each year, and they have asked for a 2016 increase for AIDS research while continuing to ignore childhood cancer research. This is not to say that AIDS funding is wrong, no doubt there has been tremendous accomplishment in this area, but to illustrate the impact of significant investment.

Currently the NCI offers that it provides around \$200 million of its \$5 billion budget to childhood cancer research. Childhood cancer research is not a line item in the NIH/NCI budget and rarely mentioned. The \$200 million level identified by NCI as benefitting childhood cancer research, is not actually dedicated to childhood cancer research projects. As far as I can determine by looking at the public information, the \$200 million is made up of percentages of grant projects that estimate impact on childhood cancer.

*As reported by The Atlantic in a January 2013 article, “there is not enough funding for childhood cancer, specifically. The National Cancer Institute, a government organization, provides funding for researchers, but only 10 percent of them can move forward with their findings due to budget cuts. Most of the financial support researchers receive is from philanthropists. In the meantime, research that could benefit children on an individual level stays in the lab, and doctors prescribe the same regimens that can be successful, but can also hurt the patient in several ways. Researchers say they are working hard to discover new theories*

March 25, 2015

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**Testimony addressing National Institute of Health (NIH) 2016 Budget Request**

*and treatments, but they feel they are being held back."* The article goes on to quote, Dr. William Carroll, researcher and director of the cancer institute at New York University saying, *"Ninety-six percent of grants (sic childhood cancer) don't get funded ... There's no doubt there's less funding available, and it's driving people out of the field."*

The Director of NIH has spoken about the budget stressor put on scientific opportunities, *the throwing away of "innovative, talented research proposals"* and the *"serious risk of losing the most important resource we have, which is this brain trust, the talent and creative energies of this generation of scientists."* I would counter that many childhood cancer research proposals are thrown away due to the lack of Federal research funding and that we have no idea about the potential brain trust of the thousands of children lost and maimed each year because of the decision that childhood cancer research is not a priority

I'm nobody special, just a mother and grandmother. I understand that I don't know much compared to the brilliance of scientists at NIH. I understand that the budget process is hard work for the committees, and resources are limited. But my experience over the past 5 years compels me to fight for kids. I can't do anything to change what happened to our sweet Declan, but I believe research will result in more funding for those deadly childhood cancers. Much like the prognosis has changed for ALL over the past decades, I believe research could provide pediatric treatments and protocols that will offer cures to children like Declan in the future. We can't keep condemning these kids to death year after year and do nothing because of money – they deserve the best that we and science can offer.

Thank you for the opportunity to offer my thoughts.

March 25, 2015



Council of Professional Associations on Federal Statistics  
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**Submitted Testimony: The Integrity of Labor, Health, and Educational Statistics**

**Submitted March 31, 2015 by: Katherine Smith, Executive Director, Council of Professional Associations on Federal Statistics**

**Supporting Direct Appropriations of \$633 million for the Bureau of Labor Statistics, \$160 million for the National Center for Health Statistics and \$300 million for the National Center for Education Statistics**

The purview of the House Labor, Health and Human Service, Education and Related Agencies Appropriations Subcommittee includes the programs of three of the 13 Principal Statistical Agencies of the U.S. – The Bureau of Labor Statistics (BLS), the National Center for Health Statistics (NCHS), and the National Center for Educational Statistics (NCES). From these three agencies come the measures by which we gauge our nation’s progress in creating jobs and assuring adequate wages, in the status of our population’s health in relation to myriad factors, and the educational achievements of our youth in relation to U.S. employment needs and relative to other countries.

The products of these three agencies have myriad users and uses. Among other things, BLS statistics are used by firms in all business sectors to make business decisions; they inform wage and employment policies at local, state and federal levels; and educational guidance counselors depend on them to provide accurate information on different professions and jobs. NCHS compiles statistical information to help guide public health and health policy decisions at all levels of government, support biomedical and health services research, and gauge effectiveness

of various health interventions. NCES documents the performance of school systems and other educational opportunities to assess adult literacy, levels of educational achievement from early childhood through elementary, secondary, and post-secondary schools. These data provide a basis for comparisons of U.S. performance with international measures, and among U.S. states. They inform everything from school bullying policies and educational technology decisions, to local, state and federal decisions on educational programs. Everyone in the U.S. has a stake in the effectiveness of these 3 statistical agencies.

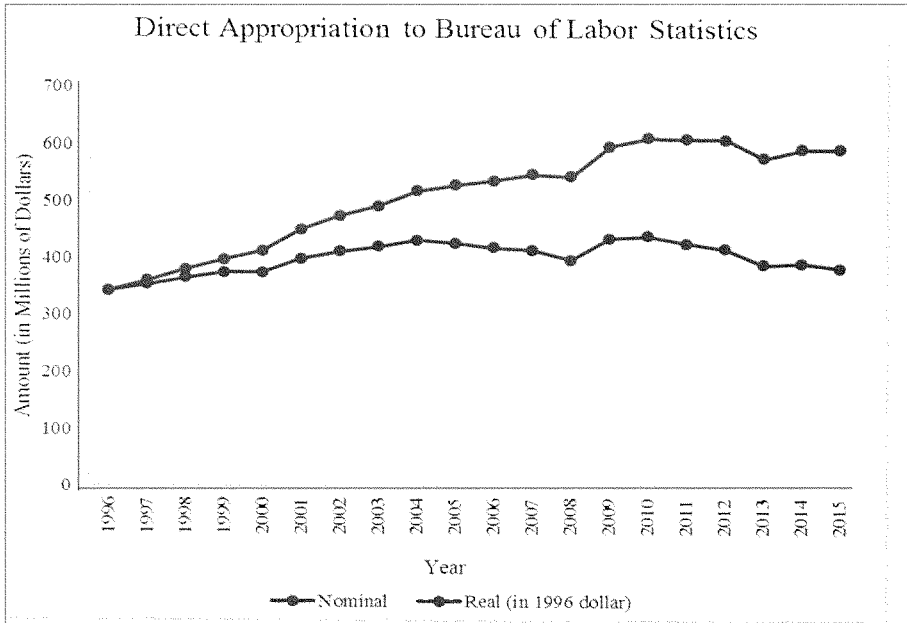
Officially designated statistical agencies must adhere to the rigorous legislative requirement of the Confidential Information Protection and Statistical Efficiency Act and live up to the standards of several Statistical Directives. They have decades (some have centuries) of experience in assuring privacy and confidentiality. Maintaining high quality while providing accurate, objective, reliable, timely, and available statistics and assuring confidentiality has several implications for their programs. First, they can't just scale down programs. A survey will not be accurate or reliable if its sample size is too small. Thus, when cost-constrained, they eliminate entire programs (always with strongly opposing stakeholders) rather than jeopardize the quality of programs across the board. Second they need to be able to invest in the quality and continued development of their highly technical staff, or risk falling behind in skills and advances in statistical methodology. They fight low wages and high hiring process complications relative to the private sector.

In FY 2015, the budgets of BLS, NCHS, and NCES are just at (in the case of NCHS) or well below (in the case of BLS) the level of funding required for them to cover all of their core responsibilities and maintain staff and technical quality. In fact, the Bureau of Labor Statistics has been operating at relatively the same inflation-adjusted appropriation level that it had in 2008 (Figure 1).

We at the Council of Professional Associations on Federal Statistics are concerned on behalf of the users of these federal statistics that their statistical integrity not be sacrificed in the face of decisions about “sexier” programs. Those non-statistical programs won’t be as effective, or we won’t be able to judge their effectiveness, without adequate, high quality statistics.

Thank you for the opportunity to submit this testimony. If it is not selected for inclusion in the hearing, please make it written testimony for the record.

Figure 1: Actual (Nominal) and Inflation-adjusted (Purchasing Power) Direct Appropriations to the Bureau of Labor Statistics, 1996-2015. Source: annual "Statistical Programs of the United States Government," Office of Management and Budget





**N**ational **C**ouncil of **S**tate **D**irectors of **A**dult **E**ducation

**Jennifer Foster, Chair**

Dr. Lennox McLendon, Senior Advisor

Dr. Art Ellison, Policy Chair

Dr. Eugene Sofer, Government Relations

**The National Council of State Directors of Adult Education offers this testimony Submitted to the House Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies to Address Funding Levels in the Department of Education for Adult Education and Family Literacy**

The National Council of State Directors of Adult Education (NCSDAE) appreciates the opportunity to submit testimony about the funding level for Adult Education programs in the Administration's FY 2016 Budget.

Adult education serves adults, 16 years of age and older, who are no longer in school or are functioning below the high school completion level. Services include teaching foundation skills like reading, math, and English coupled with college and career readiness skills that lead to adult secondary education and the transition to post-secondary education. Public schools, community colleges, and community-based organizations provide programs at the local level.

NCSDAE believes that funding for Adult Education in FY16 should be at \$622.3 million, the level authorized in the Workforce Innovation and Opportunity Act (WIOA) in 2014. Just last year, Congress passed WIOA by overwhelmingly bi-partisan votes in both the House (415-6) and Senate (97-3). The law established Adult Education as one of the four key programs in the workforce system because it recognized the crucial role Adult Education plays in educating our population, teaching English and civics, and preparing adults for occupational training and to enter the workforce or improve their employment status.

**Such improvements as the law anticipates cannot be fully realized without sufficient resources.**

The President's request of \$569 million is approximately \$53 million below the level Congress authorized (\$622.3) in WIOA and is insufficient to the challenges facing Adult Education. These

challenges include:

- Only 1.7 million of the 93 million who could benefit can access adult education services.
  - One million school age children drop out of school each year adding to that number.
- Thirty percent (30%) of foreign born speak English “not very well” or “not at all.” Fourteen million are limited English proficient.
  - Only 678,000 can currently access adult education services
- Over 40% of the 2.3 million incarcerated adults have not finished high school.
- The primary indicator of a child’s success in school is the education level of the parent; especially the mother.
- In the most recent (2010) NCSDAE survey, there were waiting lists in adult education programs in every state but one.

The challenges of attempting to provide access to adult education services are overwhelming.

Without access, those undereducated, under prepared adults cannot qualify for jobs with family sustaining incomes that require not only a high school equivalency, but also some college—preferably a one or two year certificate in a high demand occupation.

Adults without a high school diploma or functioning below a high school level, cannot qualify for either community college programs or high demand occupations.

According to the National Assessment of Adult Literacy, more than 93 million Americans, about 60 percent the workforce, lack literacy at a level needed to enroll in postsecondary education or job training that current and future jobs now require. In the decade just ended, 24 of the 30 fastest-growing occupations required workers with postsecondary education or training. About 40 percent of job openings will soon require such skills.



Thirty-two (32) states need more adults with college degrees to reach international competitiveness. **States cannot close the gap with traditional college students. They must rely on the re-entry pipeline—getting older adults back into the education system and on track to attaining college degrees.**

High schools cannot provide business and industry the workers they needs.

- There are approximately 150 million adults in the workforce.
  - The public schools graduate approximately three million young people every year which equates to only 2% of the current workforce.
  - Projected ten years out, public schools can provide only 20% of the 2025 workforce.
- The other 80% are adults in the workforce or preparing to enter the workforce today.

**Most of America's workforce of tomorrow is already in the workforce. They are beyond the reach of the high schools and postsecondary education. Adult education is the best way to re-engage them.**

Further, the Census Bureau projects that between 2000 and 2015, net international immigration will account for more than half of our nation's population growth, increasing even more the demand for adult English-language programs for adults.

By neglecting the adult population in need of education, we also harm the prospects of the next generation—57 percent of children whose parents don't have a college education live in low-income families, and are less likely themselves to get a good education qualify for family-sustaining jobs.

One in four working families in our country is low income, and postsecondary education or job training can be a ticket to the middle class for low-wage workers seeking better jobs.

The reality is that our adult education programs—for which federal funding is the core support—are reaching fewer than 2 million adults a year, just the tip of the iceberg. For all intents and purposes, Adult Education State Grants have been essentially frozen since FY 2002. Adjusted for inflation, this is a reduction of 25 percent. Enrollment has decreased most sharply among the low-income populations that most need adult education and workforce skills services. **Waiting lists exist in virtually every state.**

A robust adult education system is essential if we are to achieve our nation's economic goals. It will be impossible to create a workforce skilled enough to compete in the global 21<sup>st</sup> Century economy if we focus only on secondary schools and postsecondary institutions. Adult education must also be supported.

**Education levels correlate highly to employment and income levels, but significant underinvestment in adult education and workforce skills development is eroding America's global competitiveness.**

Other nations are fast outstripping America in boosting the educational levels of their young and working age adults. They are showing consistent decade-to-decade progress in enhancing the education levels of their adult populations, while the U.S. is losing ground.

According to the results of The Program for International Assessment of Adult Competencies (PIAAC) conducted under the auspices of the Organization for Economic Cooperation and Development (OECD) and published in 2013, “the U.S. average on the literacy and numeracy scales is mediocre at best ....” PIAAC also reports that:

- U.S. adults scored below the international average in all three domains [literacy, numeracy, and problem solving in technology-rich environments]
- US adults with more than a high school education have literacy skills similar to their

peers in other countries. ... However, U.S. adults with less than a high school diploma scored lower than their peers internationally, especially in literacy and numeracy.... In fact, the gap in average scores between adults with the highest and lowest levels of educational attainment was greater in the United States than in any other participating country, for both literacy and numeracy.

In short say the authors of the Report, “These PIAAC results confirm that skills do make a difference and suggest that we can have a substantial impact on economic success and the quality of life in the United States by enhancing skill levels across all groups within the adult population.” Unfortunately, in the past decade overall adult education enrollment has declined even as the need for services has expanded rapidly.

We are well aware of the pressures that the Committee faces in this challenging budgetary environment. Nevertheless, we urge you to fund Adult Education at the level authorized in the Workforce Innovation and Opportunity Act (2014) so that the ambitious goals of that law may be realized and that Americans embark or continue on pathways that lead to good jobs and good wages. We *must* invest adequately in our Adult Education system to remain economically competitive.

**Please contact: Dr. Lennox McLendon, Senior Advisor, at: [dc2@ncsdae.org](mailto:dc2@ncsdae.org) or Gene Sofer, Director of Government Relations at: [eugenesofer@gmail.com](mailto:eugenesofer@gmail.com)**

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# American Society of Plant Biologists

*Cultivating a better future through plant biology research*

## Official Written Testimony in Support of the National Institutes of Health's

### Fiscal Year 2016 Budget

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Committee on Appropriations

U.S. House of Representatives

March 31, 2015

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research will be a critical step toward economic recovery and job creation in our nation. ***ASPB supports the maximum fiscal year 2016 appropriation for NIH and asks that the Subcommittee Members encourage increased support for plant-related research within the agency;*** 25% of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of some 4,500 professional plant biology researchers, educators, students, and postdoctoral scientists with members across the nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in

the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

### **Plant Biology Research and America's Future**

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutraceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

### **Plant Biology and the National Institutes of Health**

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.” In general, plant research aims to improve the overall human condition—be it food, nutrition, medicine or agriculture—and the benefits of plant science research readily extend across disciplines. In fact, plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems” as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and maintenance requirements that are less expensive than those required for the use of animal systems.

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

**Health and Nutrition** — Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50% of child deaths under the age of five could be attributed to malnutrition’s effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are working today to address the root cause of this problem by balancing the nutritional content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast to developing countries, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

**Drug Discovery** – Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60% of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants and support more funding opportunities similar to the "Genomes to Natural Products" which will hopefully pave the way for new plant-related medicinal research.

**Conclusion**

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, *ASPB asks the Subcommittee to provide the maximum appropriation and direction to NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.*

Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see [www.aspb.org](http://www.aspb.org).



**Written Testimony of the Emergency Nurses Association (ENA)**  
**Fiscal Year 2016 Appropriations**  
**House Appropriations Subcommittee on Labor, Health and Human Services, Education,**  
**and Related Agencies**  
**Submitted by 2015 ENA President Matthew F. Powers, MS, BSN, RN, MICP, CEN**  
**March 31, 2015**

The Emergency Nurses Association (ENA), with more than 40,000 members worldwide, is the only professional nursing association dedicated to defining the future of emergency nursing and emergency care through advocacy, expertise, innovation, and leadership. Founded in 1970, ENA develops and disseminates education and practice standards and guidelines, and affords consultation to both private and public entities regarding emergency nurses and their practice. ENA has a great interest in the work of the Senate Labor, Health and Human Services, Education Subcommittee and especially its efforts to improve the quality of emergency care for patients in the United States. For fiscal year 2016, ENA respectfully requests \$28 million for Trauma and Emergency Care Programs (HHS; ASPR), \$244 million for Nursing Workforce Development programs (HHS; HRSA), \$21.116 million for the Emergency Medical Services for Children program (HHS; HRSA), \$30.1 million to fund poison control centers (HHS; HRSA), \$150 million for the National Institute of Nursing Research (HHS; NIH), and \$8.927 million for Rural Health – Access to Emergency Devices (HHS; HRSA).

**Trauma and Emergency Care Programs**

Trauma is the leading cause of death for persons younger than 44 and the fourth-leading cause of death for all ages. In states with an established trauma system, patients are 20 percent more likely to survive a traumatic injury. Further, victims of traumatic injury treated at a Level I trauma center are 25% more likely to survive than those treated at a general hospital.

Our trauma and emergency medical systems are designed to transport seriously injured individuals to trauma centers quickly. However, due to a lack of financial resources, 45 million

Americans do not have access to a major trauma center within the “golden hour” following an injury when chances of survival are highest.

Trauma and emergency care programs, which are authorized under the Public Health Service Act, provide much-needed money to the states to develop and enhance of trauma systems. These programs are critical to the efficient delivery of services through trauma centers, as well as to the development of regionalized systems of trauma and emergency care that ensure timely access for injured patients to appropriate facilities. This modest investment can yield substantial returns in terms of cost efficiencies and, most importantly, saved lives.

Therefore, ENA respectfully requests \$28 million in FY 2016 for trauma and emergency care programs.

### **Nursing Workforce Development Programs**

The nursing profession faces significant challenges to ensure that there will be an adequate number of qualified nurses to meet the growing healthcare needs of Americans. A growing elderly population will seek healthcare services in a multitude of settings and the care they depend upon will require a highly educated and skilled nursing workforce. In addition, demand for nurses will grow because of the increased emphasis on preventative care and the growing number of Americans with health insurance. A 2014 projection from the U.S. Bureau of Labor Statistics’ *2014 Occupational Outlook Handbook* anticipates that the number of practicing RNs will grow 26 percent by 2020 and the employment of Advanced Practice Registered Nurses will grow even more rapidly.

At the same time, the aging of the Baby Boom generation will deplete the nursing ranks as well. During the next 10 to 15 years, approximately one-third of the current nurse workforce will reach retirement age. The retirement of these experienced nurses has the potential to create a serious deficit in the nursing pipeline. At the same time, our colleges cannot keep up with the demand for new nurses. According to a 2013-2014 survey by the American Association of

Colleges of Nursing, 78,089 qualified applications were turned away from nursing schools in 2013 alone.

Title VIII Nursing Workforce Development programs address these factors and help support the training of qualified nurses. They not only enhance nursing education at all levels, from entry-level to graduate study, but they also support nursing schools that educate nurses for practice in rural and medically underserved communities. Another important part of Title VIII is the Faculty Loan Program which is critical to alleviating the large shortage in nursing faculty. Overall, more than 65,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, ENA respectfully requests \$244 million in FY 2016 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act.

### **Emergency Medical Services for Children**

The Emergency Medical Services for Children (EMSC) program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state-of-the-art emergency medical care for ill and injured children or adolescents; that pediatric services are well integrated into an EMS system backed by optimal resources; and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

The federal investment in the EMSC program produces a wide array of benefits to children's health through EMSC State Partnership Grants, EMSC Targeted Issue Grants, the Pediatric Emergency Care Applied Research Network, and the National EMSC Data Analysis Resource Center.

Therefore, ENA respectfully requests \$21.116 million in FY 2016 for the EMSC program.

### **Poison Control Centers**

Poisoning is the second most common form of unintentional death in the United States. In 2009, 31,768 deaths nationwide were attributed to unintentional poisoning. Children are especially vulnerable to injury by poisoning and each day 300 children are treated for poisoning in emergency departments across the country and two die.

The nation's 55 poison control centers handle 3.4 million calls each year, including approximately 680,000 calls from nurses and doctors who rely on poison centers for an immediate assessment and expert advice on poisoning cases.

Not only are America's network of poison centers invaluable for treating victims of poisonings, but the work of the centers also results in substantial savings to our healthcare system. About 90 percent of people who call with poison emergencies are treated at home and do not have to visit an emergency department. In more severe poisoning cases, the expertise provided by poison control centers can decrease the length of hospital stays. It has been estimated that every dollar spent on America's poison control centers saves \$13.39 in health care costs and lost productivity. The positive impact to the federal budget is also significant. A 2012 study by the Lewin Group found that poison control centers resulted in \$313.5 million in savings to Medicare and \$390.2 million in savings to Medicaid.

Therefore, ENA respectfully requests \$30.1 million in FY 2016 for poison control centers.

### **The National Institute of Nursing Research (NINR)**

As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR's mission is to promote and improve the health of individuals, families, communities, and populations. The Institute supports and conducts clinical and basic research on health and illness to build the scientific foundation for

clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.

NINR nurse-scientists examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. Our country must look toward prevention as a way of reducing healthcare expenditures and improving outcomes. The work of NINR is an important part of this effort.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our nation's nursing schools.

Therefore, ENA respectfully requests \$150 million in FY 2016 for the NINR.

### **Rural and Community Access to Emergency Devices Program**

Fewer than 10 percent of people who suffer a cardiac arrest outside of a hospital setting survive. According to a 2011 study published in the New England Journal of Medicine, immediate CPR and prompt defibrillation using an automated external defibrillator (AED) can more than double a patient's chance of survival.

The Health Resources and Services Administration (HRSA)'s Rural and Community Access to Emergency Devices Program saves the lives of patients with cardiac arrest. Between August 1, 2008, and July 31, 2010, nearly 800 cardiac arrest victims were reportedly saved through this program. Funding for this initiative is used to buy AEDs, locate them in public places where cardiac arrests are more likely to happen, and instruct lay rescuers and first responders in their use. Between March 1, 2010, and Feb. 28, 2011, 3,928 AEDs were placed and 28,776 people were trained in their use.

Therefore, ENA respectfully requests \$8.927 million in FY 2016 for the Rural and Community Access to Emergency Devices Program.

Paul Krebsbach, DDS, PhD President (2015-2016)  
 American Association for Dental Research, Public Witness Testimony  
 House Labor, Health and Human Services and Education Appropriations Subcommittee  
 April 1, 2015

On behalf of the 3,600 individual and 54 institutional members of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's fiscal year 2016 requests, which includes at least **\$32 billion for the National Institutes of Health (NIH) and \$425 million for the National Institute of Dental and Craniofacial Research (NIDCR)**. These funding recommendations represent the minimal needs of the research community while at the same time taking into consideration the continued tight budget climate dictated by the caps established by the *Budget Control Act of 2011*.

I want to emphasize, the current austerity frame is unworkable and insufficient to meet our nation's mounting health demands. According to our members, when sequestration hit it was a game-changer. Established faculty had difficulty getting grants renewed, new faculty hit a funding wall and people employed by laboratories in communities throughout the country lost their jobs. Moreover, the current budget climate creates an atmosphere that is very discouraging to new scientific investigators whose research proposals are good enough to be funded, but were not because of the budget cuts. We are at risk of losing them and their promising research ideas—ideas that might lead to significant advances in dental, oral health and craniofacial health. We therefore strongly urge Congress to take the steps necessary to put an end to sequestration permanently and reinvest in America's health.

It is important to note that when adjusted for inflation, the NIDCR budget is 25 percent, or \$94 million, less than it was in 2004, resulting in the lowest number of grants awarded in 14 years. This decline in purchasing power is particularly troubling because the improvements in oral health during the last half century are largely credited to research

supported by NIDCR. This decline in funding will slow or limit future breakthroughs. NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions make it difficult to eat, drink, swallow, smile, talk and maintain proper nutrition. Scientists also have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes and pancreatic cancer.

In spite of these improvements, however, treating oral health conditions is costing this nation \$111 billion in expenditures on dental services in 2013. While tooth decay and gum disease remain the most prevalent cost-drivers, complete tooth loss, oral cancer and craniofacial congenital anomalies, such as cleft lip and palate, are also health and economic burdens to the American people. Moreover, oral health disparities persist for many racial and ethnic groups. By providing **\$425 million** in fiscal year 2016 for NIDCR, dental, oral and craniofacial researchers will be able to build upon the gains of past decades, creating less invasive, cost-effective and more efficient ways to improve oral health. Below are some examples highlighting the important work supported by NIDCR:

- **Precision Oncology:** NIDCR-funded researchers are investigating the role genetics play in head and neck cancers, and paving the way for efforts in precision oncology. Examining genetic data may lead to a better understanding of these diseases, leading to the identification of biomarkers that will allow for earlier—perhaps life-saving—detection and enable more effective treatment of head and neck cancers.

- **Point of Care Diagnostics:** Salivary diagnostics are measures that draw and analyze saliva to test for conditions such as HIV, human papillomavirus (HPV), substance abuse, caries, periodontitis and oral cancer. As a result of research supported by NIDCR over the last decade, diagnostics also are showing great promise in screening for diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer.
- **Dental Caries:** Dental caries, or tooth decay, remain the most prevalent chronic disease in both children and adults resulting in a substantial economic and health burden to the American people. Although caries has significantly decreased for most Americans over the past four decades, disparities remain among some population groups. Additional research is needed to enhance efforts to address dental caries including studies on oral microbiology, oral health literacy and the reduction of free sugars as having additional health benefits.
- **Enhanced Tissue Regeneration:** NIDCR-funded scientists have developed effective techniques to prevent inflammation from interfering with the use of stem cells to form bone and cartilage for oral, dental and craniofacial purposes. The isolation and enrichment of stem cells is also being explored, which would enhance the cells' ability to regrow bone and cartilage, with potential impacts throughout the health sciences sector.
- **Cleft Lip and/or Cleft Palate:** Craniofacial anomalies such as cleft lip and/or cleft palate are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Studies supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions.
- **Evidenced-Based Practice:** NIDCR awarded a seven-year grant that consolidates its dental practice-based research network initiative into a unified nationally coordinated effort.



The consolidated initiative, the National Dental Practice-Based Research Network (NDPBRN) is headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral health care. These studies help to expand the profession's evidence base and further refine care.

Our members remain concerned that unless Congress provides NIH with stable, predictable and increased funding our ability to attract the next generation of scientists will stall; the nation's standing as a world leader in science will decline; and innovation necessary to push the boundaries of research will be stymied. Future advances in health care depend on a sustained investment in basic research to identify the fundamental causes and mechanisms of disease, accelerate technological development and discovery, and ensure a robust pipeline of creative and skillful biomedical researchers. For these reasons, I implore you to work in a bipartisan manner and provide funding increases for NIH and NIDCR in fiscal year 2016.

In addition to the NIH, AADR members care deeply about the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, the Centers for Disease Control and Prevention (CDC) Division of Oral Health's public health prevention efforts, data from the National Center for Health Statistics (NCHS) and the Agency for Healthcare Research & Quality (AHRQ). Please support AADR's funding recommendations for these agencies depicted in the chart on the following page.

Agency	FY12	FY13	FY14	FY15	FY16 PBR	FY16 AADR
<b>NIH</b>	<b>30.7 b</b>	<b>29.3 b</b>	<b>30 b</b>	<b>30.3b</b>	<b>31.3b</b>	<b>32 b</b>
<b>NIDCR</b>	<b>410.3</b>	<b>386.8m</b>	<b>397.8m</b>	<b>397.7m</b>	<b>406.7m</b>	<b>425 m</b>
NCATS	574.8m	542.1m	631.5m	635.2m	660.1m	660.1m
AHRQ	405.1m	429.4m	371m	364m	276m	375m
CDC, Oral Health	14.6m	13.8m	15.7m	15.7m	15.7m	20.0 m
CDC, NCHS	153.8	153.8	155.3	155.4m	172m	172 m
HRSA, Title VII Oral Health	32.4m	30.7m	32m	33.9m	33.9m	35.0 m

Thank you for the opportunity to submit this testimony. AADR stands ready to answer any questions you may have.

**UNITED TRIBES TECHNICAL COLLEGE**

3315 University Drive, Bismarck, North Dakota 58504

Leander "Russ" McDonald, PhD, President, [lmcdonald@uttc.edu](mailto:lmcdonald@uttc.edu); 701-255-3285

FY 2016 Department of Education Appropriations:

*Carl Perkins Act (Tribally Controlled Postsecondary Career and Technical Institutions);**Higher Education Act (Title III); Perkins Grants*

Submitted to the House Labor-HHS-Education Appropriations Subcommittee

April 2, 2015

United Tribes Technical College (UTTC) has for 46 years, and with the most basic of funding, provided postsecondary career and technical education and family services to some of the most impoverished high risk Indian students from throughout the Nation. Despite such challenges, we have consistently had excellent retention and placement rates and are a fully accredited institution. We are proud to be preparing our students to participate in the new energy economy in North Dakota and to be part of building a strong middle class in Indian Country by training the next generation of law enforcement officers, educators, medical providers, welders, technicians, and administrators. We are governed by the five tribes located wholly or in part in North Dakota. *We are not part of the North Dakota state college system and do not have a tax base or state-appropriated funds on which to rely.* The requests of the UTTC Board are:

- *\$10 million for base funding authorized under Section 117 of the Carl Perkins Act* for the Tribally Controlled Postsecondary Career and Technical Institutions program. This is \$2.3 million above the FY 2015 level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula that is not so reliant on Indian Student Count to avoid dramatic swings in annual awards.

- *Forward Funding.* We ask that the Section 117 Perkins funds, like the other funds under the Carl Perkins Career and Technical Education Act, be put on a forward funded basis.
- *\$30 million as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act,* \$4.3 million above the FY 2015 level.
- *Support the scheduled increase in the maximum Pell grant award from \$5,775 to \$5,916.*

Section 117 Perkins Funding. We are extremely disappointed that neither the FYs 2014 nor 2015 Appropriations Acts restored the FY 2013 sequestration to Section 117 Perkins even though funding for the rest of the Perkins Act was restored. Perhaps Section 117 was overlooked as a source of job training as it is in the Higher Education portion of the budget. We all realize the urgent need to better prepare a workforce to meet industry and other emerging needs. We are part of that undertaking, but need more resources to come closer to our potential.

Perkins funds are central to the viability of our core postsecondary education programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time targeted supplemental funds. Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary funds.

We highlight several relatively recent updates of our curricula to meet job market needs. Indeed, the ramifications of the North Dakota Bakken oil boom are apparent as we have seen faculty and students leave education in pursuit of jobs in the Bakken region. We saw the need for more certified welders in relation to the oil boom and have expanded our certified welding program in response to the workforce need. We are now able to train students for good paying in-demand welding employment with a focus on career rather than just a job. Other courses reflect new innovative approaches on energy auditing and Geographic Information System

Technology. UTTC is seeing increased interest in our online programs of study and short term skill building training at the UTTC Black Hills Learning Center, a distance learning site located at Rapid City, SD. We are also working toward the establishment of an American Indian Specialized Health Care Training Clinic on our established Bismarck, ND campus.

*Funding for United Tribes Technical College is a good investment. We have:*

- Renewed unrestricted accreditation from the North Central Association of Colleges and Schools, for July 2011 through 2021, with authority to offer all of our full programs on-line. We have 16 Certificate, 20 Associate, and three Bachelor degree program. Five programs are fully developed and available as online programs.
- Services including a Child Development Center, family literacy program, wellness center, area transportation, BIE-funded K-8 elementary school, tutoring, counseling, family and single student housing, and campus security.
- A projected return on federal investment of 20-1 (2005 study).
- A semester retention rate of 68% and a graduate placement rate of 79%. Over 45% of our graduates move on to four-year or advanced degree institutions.
- Students from 49 tribes; 73% of our undergraduate students receive Pell Grants.
- An unduplicated count of 605 undergraduate degree-seeking, 258 continuing education, and 42 dual credit enrollment students for a total of 905 for 2014-2015.
- A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.
- A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. A North Dakota State University study reports

that the five tribal colleges in North Dakota made a direct and secondary economic contribution to the state of \$181,933,000 in 2012.

*Forward Funding.* We ask that the Appropriations Committees provide one-time funding for Section 117 Perkins to put it on a forward funded basis. We do not know why it is not already forward funded, given that the rest of the Perkins Act is forward funded. A number of years ago Section 117 was moved to the Higher Education portion of the budget even though it is authorized through the Perkins Act. Perhaps that has something to do with it, although we note that many education programs are forward funded. Forward funding allows planning for vital education programs before the start of each school year, which is critically important when appropriations are delayed and the government is funded via Continuing Resolutions.

*Title III-A (Section 316) Strengthening Institutions.* The Title III-A Strengthening Institutions funding is very important for all the tribal colleges. Funds are distributed via a formula with up to 30 percent of funds authorized to be set-aside for competitive funding for facility construction and maintenance. We share with other tribal colleges serious issues of inadequate physical infrastructure.

We are constantly in need of additional student housing, including family housing. With the completion of a Science, Math and Technology building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. While we have constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of what was Fort Abraham Lincoln, as well as housing that was donated by the federal government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper than rehabilitating the old buildings that now house students.

Pell Grants. We support maintaining the Pell Grant program and letting scheduled increases occur. We oppose the House Budget Resolution that calls for a ten-year freeze on the program. This resource makes all the difference in whether most of our students can attend college. As noted above, 73 percent of our undergraduate students receive Pell Grants.

The Duplication or Overlapping Issue. As you know in March 2011, the Government Accountability Office issued two reports regarding federal programs which may have similar or overlapping services or objectives (GAO-11-474R and GAO-11-318SP). Funding from the BIE and the DOE's Carl Perkins Act were among the programs listed in the reports. *The full GAO report did not recommend defunding these programs; rather, the possibility of consolidation of these programs was proposed to save administrative costs.* We are not in disagreement about possible consolidation of our funding sources, as long as program funds are not cut.

The Perkins funds supplement, but do not duplicate, the BIE funds. *Both sources of funding are critical to frugally maintaining our institution.* We actively seek alternative funding to assist with academic programming, deferred maintenance, and scholarship assistance, among other things. The need for career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding. There are only two institutions targeting American Indian/Alaska Native career and technical education and training at the postsecondary level—UTTC and Navajo Technical University. Combined, these institutions received less than \$14.7 million in FY 2015 federal operational funds (\$7.7 million from Perkins; \$6.9 million from the BIE). That is not an excessive amount for two campus-based institutions who offer a broad array of programs geared toward the educational and cultural needs of their students and who teach job-producing career skills.

Thank you for your consideration of our requests.



# COUNCIL ON SOCIAL WORK EDUCATION

STRENGTHENING THE PROFESSION OF SOCIAL WORK  
*Leadership in Research, Career Advancement, and Education*

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## Testimony for Fiscal Year 2016

### Department of Health and Human Services and Department of Education Funded Programs

Submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related

Agencies; Committee on Appropriations; United States House of Representatives

April 2, 2015

Submitted by

Dr. Darla Spence Coffey, President, Council on Social Work Education

Phone: (703) 683-8080; E-mail: [DCoffey@cswe.org](mailto:DCoffey@cswe.org)

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. CSWE is a nonprofit national association representing more than 2,500 individual members and more than 700 master's and baccalaureate programs of professional social work education. CSWE requests:

Agency	Account	Program	Funding Requested
HHS	HRSA	Title VII and Title VIII Health Professions Programs	\$524 million
HHS	HRSA	Title VII Mental and Behavioral Health Education and Training Program	\$10 million
HHS	SAMHSA-HRSA	SAMHSA-HRSA Behavioral Health Workforce Education and Training Grant Program	\$56 million
HHS	SAMHSA	Minority Fellowship Program	\$10.7 million, including at least \$5.4 million for MFP core activities
ED	N/A	Pell Grant	\$5,915 for the maximum Pell Grant
ED	N/A	GAANN	\$31 million
ED	N/A	Loan Repayment Programs	Support without a cap on repayment
HHS	NIH	Overall Funding For NIH	\$32 billion



## HRSA TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide \$524 million in FY 2016 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). Specifically, CSWE recommends \$280 million for Title VII. These health professions programs represent federal programs designed to train health care providers in an interdisciplinary way to meet the health care needs of all Americans, including the underserved and those with special needs, and expand minority representation in the health care workforce. The Title VII and Title VIII programs, for which social workers and social work students are eligible, provide loans, loan guarantees, and scholarships to students, as well as grants to institutions of higher education and non-profit organizations to help build and maintain a robust health care workforce.

Funding through Title VII supports the **Mental and Behavioral Health Education and Training (MBHET) Grants Program** which provides grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment, as well as professional education and training. “In Academic Year 2013-2014, the Mental and Behavioral Health Education and Training (MBHET) grants supported more than 190 graduate-level students participating in either a social work practicum or a pre-degree internship in clinical psychology.”<sup>1</sup>

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<sup>1</sup> Department of Health and Human Services FY 2016, Health Resources and Services Administration, *Justification of Estimates for Appropriations Committees*, <http://www.hrsa.gov/about/budget/budgetjustification2016.pdf>, Retrieved March 3, 2015, Pg 152.

Also, CSWE supports the creation of the **Clinical Training in Interprofessional Practice Program**, funded in the President's FY 2016 Budget Request, as long as it would include social workers. This program would promote the training of interprofessional teams that can provide high quality care for patients and communities. In these teams, CSWE encourages the explicit inclusion of social workers.

#### **SAMHSA/ HRSA BEHAVIORAL HEALTH WORKFORCE EDUCATION AND TRAINING PROGRAM**

The Behavioral Health Workforce Education and Training (BHWET) Program, a partnership between HRSA and the Substance Abuse and Mental Health Services Administration (SAMHSA), builds on HRSA's mental and behavioral health training efforts by providing grant funding for the mental health and substance abuse workforce serving children, adolescents, and transitional-age youth at risk for developing, or who have developed, a recognized behavioral health disorder.<sup>2</sup> In 2015, the program's first year, social work programs were awarded about \$19,087,780 and we estimate about 4,196 students will be served through BHWET. **CSWE urges the Committee to support \$56 million for the SAMHSA-HRSA BHWET Grant Program**, which is a \$21 million increase above the FY 2015 enacted level and supports the President's FY 2016 request.

#### **SAMHSA MINORITY FELLOWSHIP PROGRAM**

**CSWE urges the Committee to appropriate the highest level possible for the SAMHSA Minority Fellowship Program (MFP) in FY 2016.** The goal of the MFP program is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental

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<sup>2</sup> [http://www.integration.samhsa.gov/integrated-care-models/safety\\_net\\_providers](http://www.integration.samhsa.gov/integrated-care-models/safety_net_providers)

health and substance use fields.<sup>3</sup> CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. In addition, CSWE also administers funds for the Minority Fellowship Program-Youth (MFP-Y). This program reduces health disparities and improves behavioral health care outcomes for racially and ethnically diverse populations by increasing the number of culturally competent master's-level behavioral health professionals serving children, adolescents, and populations in transition to adulthood (aged 16–25).

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program continues to struggle to keep up with the demands facing these health professions. **The President's FY 2016 budget request includes \$10.7 million to support six MFPs, two MFP-Y, two MFP-AC grants, and three technical assistance and evaluation support contracts. CSWE urges the Committee to support this request, including at least \$5.4 million for MFP core activities.**

#### DEPARTMENT OF EDUCATION: STUDENT AID PROGRAMS

**CSWE supports full funding to keep the maximum Pell Grant at \$5,915 in FY 2016.** While Congress is understandably focused on identifying a solution that will place the Pell Grant program fiscally on solid ground, we urge you to remember that these grants help to ensure that all students, regardless of their economic situations, can achieve higher education. The Graduate Assistance in Areas of National Need (GAANN) program provides graduate

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<sup>3</sup> According to SAMHSA, minorities make up over one-fourth of the population, but less than 20 percent of behavioral health providers come from ethnic minority communities. Retrieved from SAMHSA Minority Fellowship Program, <http://www.samhsa.gov/minorityfellowship/>.

traineeships in critical fields of study. Currently, social work is not defined as an area of national need; however, it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008. We encourage ED to include social work in the GAANN program in future years. Inclusion of social work would significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. **CSWE urges the Subcommittee to provide the FY 2012 pre-sequester funding level of \$31 million for the GAANN Program and include social work as an area of national need.**

CSWE supports ED efforts to help students with high debt loads serve in low paying positions. The Income-Based Repayment (IBR) program and the Public Service Loan Forgiveness programs help students graduating from social work programs who wish to serve in high-needs communities. **CSWE urges the Subcommittee to support loan repayment programs without a cap on repayment support at ED.**

#### **NIH: SUPPORT FOR RESEARCH**

**CSWE supports at least \$32 billion for the National Institutes of Health (NIH) in FY 2016** and advocates for continued investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to better understand, and appropriately address, the needs of high-risk populations including children, racial and ethnic minority populations, and geriatric populations.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

**Kim Bischoff, Executive Director**

**The Neurofibromatosis (NF) Network**

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your Fiscal Year 2016 Labor, Health and Human Services, Education Appropriations bill.

*Neurofibromatosis [NF] – The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair, learning disabilities, autism and attention deficit disorders. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 basic and clinical research.*

On behalf of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large part to this Subcommittee's strong support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, pain, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and is more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which initially involves tumors causing deafness and balance problems, and Schwannomatosis, the hallmark of which is severe pain. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these

disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

### ***Learning Disabilities/Behavioral and Brain Function***

Learning disabilities affect one-half of people with NF1. They range from mild to severe, and can impact the quality of life for those with NF1. In recent years, research has revealed common threads between NF1 learning disabilities, autism and other related disabilities. New drug interventions for learning disabilities are being developed and will be beneficial to the general population. Research being done in this area includes a clinical trial of the statin drug Lovastatin, as well as other categories of drugs.

### ***Bone Repair***

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

### ***Pain Management***

Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF

research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

### ***Nerve Regeneration***

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

### ***Wound Healing, Inflammation and Blood Vessel Growth***

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

### ***New Cancer Treatments***

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70% of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. One of these



tumor types is malignant peripheral nerve sheath tumor (MPNST), a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from \$3 million in FY1990 to \$21 million in FY2014. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

Statement of the Institute of Makers of Explosives (IME)  
 Submitted April 2, 2015 by  
 Cynthia Hilton, Executive Vice President  
[chilton@ime.org](mailto:chilton@ime.org)

For the Subcommittee on Labor, HHS, Education, and Related Agencies  
 U.S. House of Representatives

FY 2016 DOL Budget Request for the Occupational Safety and Health Administration (OSHA)

Interest of IME

IME is a nonprofit association founded in 1913 to provide accurate information and comprehensive recommendations concerning the safety and security of commercial explosive materials. Our mission is to promote safety and the protection of employees, users, the public and the environment, and to encourage the adoption of uniform rules and regulations in the manufacture, transportation, storage, handling, use and disposal of explosive materials used in blasting and other essential operations.

IME represents U.S. manufacturers and distributors of commercial explosive materials and oxidizers as well as other companies that provide related services. Millions of metric tons of high explosives, blasting agents, and oxidizers are consumed annually in the U.S. Of this, IME member companies produce over 98 percent of the high explosives and a great majority of the blasting agents and oxidizers. These products are used in every state and are distributed worldwide.

Commercial explosives are pervasively regulated by a myriad of federal and state agencies. Explosives manufacturing, storage and transportation facilities are subject to OSHA's Explosives and Blasting Agents standard. In addition, all explosives facilities and AN manufacturing facilities comply with the Process Safety Management (PSM) standard.<sup>1</sup> OSHA participates in the Chemical Facility Safety and Security Working Group, or Interagency Working Group ("IWG"), which is engaged in satisfying the requirements of Executive Order ("EO") 13650, *Improving Chemical Facility Safety and Security*. The IWG's June 6, 2014 status report, *Actions to Improve Chemical Facility Safety and Security - A Shared Commitment*, includes actions that have the potential to significantly impact the commercial explosives industry.

We offer the following comments on OSHA's request for funds to address chemical facility safety including ammonium nitrate (AN) facilities, and the concurrent need to ensure that the agency's actions complement the regulatory requirements of other federal agencies while avoiding unnecessary regulation and/or redundancy within and between agency programs.

Background

AN is an indispensable ingredient in blasting agents used in mining, construction, and other industries critical to the U.S. economy. Currently, upwards of 75 percent of the billions of pounds of AN consumed annually is manufactured for the explosives industry. AN-based blasting agents

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<sup>1</sup> AN manufacturing facilities are covered by PSM because they use anhydrous ammonia in the manufacturing process.

have become the most widely used explosive materials in the world since their introduction in the 1950s. There is no viable alternative.

The “technical” grade of AN used in the explosives industry has the same chemical composition as the “fertilizer” grade of AN used in the agricultural sector, only the density of the prill is different. AN, in either form, is not self-reactive and does not pose a threat of an accidental release of energy or fumes unless subjected to substantial and sustained heat (e.g., fire) or shock from high explosives.

#### OSHA’s PSM Budget Request

OSHA is requesting \$23,306,000 to fund Safety and Health Standards activity.<sup>2</sup> This includes an increase in funding to support EO 13650. In connection with that effort, OSHA states that it will use the appropriation to modernize PSM as well as other standards impacting the commercial explosives industry (e.g., ammonium nitrate storage updates and clarifications in the Explosives and Blasting Agents standard), and to develop several related guidance documents in consultation with other federal agencies.<sup>3</sup> In pursuing the requirements of the EO, OSHA, in December 2013, published a Request for Information (RFI) on PSM. Among other things, OSHA inquired whether AN should be included on an expanded list of substances covered by PSM. We do not believe that any resources appropriated to support OSHA’s programs should be used to fund an expansion of the PSM program to include AN. Rather, should OSHA choose to address AN safety, its resources should be allocated to the enhancement of existing OSHA regulations governing this material.

Since 1971, the storage and handling of AN has been regulated under OSHA rules that specifically address the properties of this material. These rules at 29 CFR 1910.109(i) are part of the Explosives and Blasting Agents standard and are based on NFPA safety codes.<sup>4</sup> There is no known accidental detonation of AN where a facility has been compliant with this OSHA standard.<sup>5</sup> In fact, the safe management of AN is not complicated and is easily achieved by following very basic, well-understood safety practices. When handled in accordance with these simple tenets, AN is a stable, relatively inert material; it is not the type of highly hazardous chemical that Congress intended to cover under the PSM program. While efforts to include AN under PSM are not necessary or appropriate, we do support the appropriation of sufficient funds to allow OSHA to update 29 CFR 1910.109(i) to comport with the most recent edition of NFPA’s code addressing AN and with modern industry best practices and standards.

In support of this recommendation, we urge the Subcommittee to include the following language submitted by Representatives Charlie Dent and Evan Jenkins in the Subcommittee’s FY 2016 appropriations bill:

**(X) None of the funds made available by this Act may be used imposed new regulations on the storage of solid ammonium nitrate unless those funds are used to update section 1910.109(i), title 29, Code of Federal Regulations, to be consistent with the safety standards for the storage of solid ammonium nitrate issued by the National Fire Protection Association in publication NFPA 400 Hazardous Materials Code and such other voluntary standard-setting organization as the Secretary determines appropriate.**

<sup>2</sup> FY 2016 OSHA Congressional Budget Justification, p.24.

<sup>3</sup> Id.

<sup>4</sup> NFPA 400, Hazardous Materials Code. The 2016 edition of the code is scheduled for publication in December 2015.

<sup>5</sup> In addition, AN is subject to various ATF, EPA, DHS, and DOT safety and security regulations.

We believe that this allocation of available resources will prevent redundant and unnecessary federal regulation while ensuring the safety of commercial explosives and AN facilities and their host communities.

### Conclusion

Given the decades-long safety record of OSHA's 1910.109(i) standard on AN, imposing a complex regulatory program like PSM would impose a significant administrative and economic burden on impacted small businesses without any commensurate improvement in safety. While we support the modernization of the 1910.109(i) standard, we believe the inclusion of AN in the PSM standard would amount to over-regulation, would prove exceedingly costly, and would do nothing to enhance the safety of workers or the public. Any funding provided to OSHA should include a prohibition on the expansion of PSM to include AN.

Testimony for Submission Prepared for the Senate Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

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The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC. The coalition includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies working to increase federal support for hepatitis prevention, testing, education, research and treatment. We urge your support for increased funding for the following federal hepatitis programs in the FY2016 Labor, Health and Human Services, and Education Appropriations bill:

Agency	Program	HAP Funding Request
Centers for Disease Control and Prevention	Division of Viral Hepatitis	\$62.8 million

The Centers for Disease Control and Prevention (CDC) has estimated that up to 5.3 million people are living with chronic hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as many as 75 percent are not aware of their infection. However, these figures are based on National Health and Nutrition Examination Survey (NHANES) data, which does not include homeless and unstably housed individuals, those living in nursing homes, the incarcerated, the military, or many immigrant and migrant populations – populations disproportionately affected by viral hepatitis. Without a confirmed diagnosis and linkage to and retention in care, 15-40% of those living with viral hepatitis will eventually develop liver cirrhosis and/or liver cancer. In 2012 alone, 40,599 cases of HBV and 145,762 cases of HCV were reported to the CDC. Unfortunately, due to the lack of an adequate surveillance system, these estimates are likely only the tip of the iceberg. Without the necessary access to care and/or treatment, viral hepatitis can lead to chronic liver disease, cirrhosis, liver cancer and liver failure

and complications from these chronic infections claim between 15,000 and 50,000 lives annually. Analyses of viral hepatitis-related morbidity and mortality have found that the mortality rate attributed to viral hepatitis has increased over the last several years.

Viral hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID), men who have sex with men (MSM), persons living with HIV, Native Americans, African Americans, Asian Americans, Latinos and residents of rural and remote areas with limited access to medical treatment and culturally and linguistically-appropriate services. “Baby Boomers,” persons born between 1945 and 1965, have the greatest risk for HCV-related morbidity and mortality – 1 in 33 people born in this time period are hepatitis C positive. Both CDC and the United States Preventive Services Task Force (USPSTF) have released HBV and HCV screening guidelines recommending that providers offer a one-time HCV screening to anyone in this birth cohort, and that anyone at high-risk for HBV and HCV should be screened. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined, representing 75 percent of new HCV cases. In fact, 35 states reported increases in persons newly infected with HCV from 2010 to 2012.

Even with these challenges, the availability of effective new curative treatments for HCV, and an effective vaccine and treatments to control HBV, brings the elimination of HCV and HBV in the United States within our reach, setting the stage for an enormous new public health victory. The elimination of HCV and HBV in the United States is possible – but not without increased investments in comprehensive, national viral hepatitis prevention, screening, linkage to care, education and surveillance programs.

### **CDC Division of Viral Hepatitis**

HAP encourages funding of **\$62.8 million** for the CDC Division of Viral Hepatitis (DVH) to more effectively combat the epidemics. The CDC's 2010 professional judgment (PJ) budget recommended \$90.8 million each year from FY2011-FY2013, \$170.3 million annually from FY2014-FY2017, and \$306.3 million annually from FY2018-FY2020 for DVH to comprehensively address the hepatitis B and hepatitis C epidemics. While small in comparison, HAP's requested increase of \$31.5 million, to \$62.8 million, is in line with the needs determined by that PJ and with the goals of the *Action Plan for the Prevention, Care, & Treatment of Viral Hepatitis (Viral Hepatitis Action Plan)*. HAP recommends that these funds be used on the following priority areas, allocated in proportion to HBV and HCV burden, using available epidemiological data.

### **Screening and Linkage to Care**

At present, only 25-35 percent of people living with chronic viral hepatitis are aware of their infection. The *Viral Hepatitis Action Plan* established a goal of increasing the proportion of persons who are aware of their hepatitis infection to 66 percent for both HBV and HCV. This is why full implementation of the CDC and USPSTF recommendations for HBV and HCV testing and linkage to care by state Medicaid programs, Medicare, and private health systems and providers are so necessary. Of course, these systems do not capture all of the populations at risk. Although health departments receive no categorical funding for testing, they were able to leverage other resources to test over 125,000 people in 2013. This leveraged funding is not consistent from year to year, nor is it enough to reach those populations at highest risk for hepatitis. In the absence of a federal commitment to a nationwide awareness, testing and linkage

to care initiative, we remain concerned about the ability of the federal government to meet the goals of the *Viral Hepatitis Action Plan*.

### **Surveillance**

As testing and linkage to care activities increase and improve, strengthening local and state capacity to execute viral hepatitis monitoring and surveillance activities takes on an even greater importance. The CDC currently funds only 5 state health departments and 2 local health departments to conduct minimal surveillance in their jurisdictions. CDC also provides funds to state and local health departments, the cornerstone implementers of national public health policies, to coordinate prevention efforts via the Viral Hepatitis Prevention Coordinator Program (VHPC). The VHPC program is the only national program dedicated to the prevention and control of the viral hepatitis epidemics. This program provides funding to support a coordinator position in each jurisdiction, but provides no money for the provision of public health services, such as surveillance, public education and access to prevention services like testing and hepatitis A and B vaccinations, which must be cobbled together from other sources year-to-year. With increased investments in nationally coordinated surveillance activities, key stakeholders would be equipped with information that is critical to understanding the burden and impact of the hepatitis epidemics, identify and avert outbreaks, and that will allow for improved targeting of resources to the most impacted communities.

### **Addressing the Emerging Hepatitis C Epidemic among Young Persons at Risk**

HCV prevalence among PWIDs is as high as 70%, and between 20-30% of uninfected people who inject drugs acquire HCV each year. Unlike historical trends of HCV infections (i.e., concentration in larger, urban city centers), new HCV infections are increasingly found in suburban and rural settings, especially in Appalachia. This trend is largely due to the prescription



opiate epidemic and the transition many young people have made from using opiate pills to injecting heroin. This increase makes the need to enhance and expand these prevention efforts all the more urgent and underscores the need to prioritize immediate support in the field, strengthening health department and community responses that target youth and young adults, specifically persons who inject drugs, persons under 30 years old, and persons living in rural areas.

### **Elimination of Mother-to-Child Transmission of Hepatitis B**

Although we have made great strides in reducing the burden of HBV among newborns and young people, due in part to the success of the Perinatal Hepatitis B Coordinator program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD), between 800 to 1,000 perinatal HBV transmissions occur each year. Further, one of the greatest remaining challenges for hepatitis A and B prevention is the vaccination of high-risk adults. Additional funding at NCIRD for an Adult HBV Vaccination Initiative is necessary to prevent the transmission of HBV, and especially perinatal HBV. High-risk adults account for more than 75 percent of all new cases of HBV infection each year and annually result in an estimated \$658 million in medical costs and lost wages, despite the fact that HBV is preventable.

As you contemplate the FY2016 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that you consider these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the viral hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against these epidemics.

## Testimony for Submission

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To the House Committee on Appropriations  
 Subcommittee on Labor, HHS, Education and Related Agencies for FY2016

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV and viral hepatitis healthcare, prevention, education and supportive service programs funded by state and federal governments. On behalf of NASTAD, we urge your support for increased funding for federal HIV and hepatitis programs in the FY2016 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and hepatitis programs in FY2016:

<b>Agency</b>	<b>Program</b>	<b>NASTAD Funding Request</b>
Health Resources and Services Administration	Ryan White Part B Base	\$437.5 million
Health Resources and Services Administration	Ryan White Part B ADAP	\$943.3 million
Centers for Disease Control and Prevention	Division of HIV Prevention	\$832.7 million
Centers for Disease Control and Prevention	Division of Viral Hepatitis	\$62.8 million

The Affordable Care Act (ACA) is radically changing the U.S. health care system. The ACA provides opportunities to increase access for many people living with HIV and/or hepatitis to the care and prevention services needed to help end these twin epidemics. However, access to insurance alone does not replace the key role of state public health programs to monitor diseases within their borders. Public health will remain a critical player in meeting the needs of the hardest to reach, most vulnerable populations (e.g., men who have sex with men [MSM], youth,

persons who inject drugs) from actively identifying and locating persons at risk, to ensuring linkage to and retention in medical care in a manner that is responsive to the needs of people living with HIV and/or hepatitis.

Domestic prevention efforts must match the commitment to the care and treatment of people who are living with HIV. To be successful, we must expand traditional efforts (e.g., outreach and screening for HIV/STDs) and scale-up proven new biomedical prevention modalities such as pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), while reimagining how the compendium of effective prevention tools can work in tandem to curb incidence in the United States. We must also prioritize funding and efforts to the populations most disproportionately impacted by HIV in the United States – men who have sex with men (MSM), especially young MSM of color. Among the services necessary to improve health outcomes are the needs for linkage to, and retention in care, and access to medications that suppress viral load, reducing HIV transmission, which make HIV more difficult to transmit – ultimately leading to fewer new infections. The Centers for Disease Control and Prevention (CDC)’s prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

#### **HIV/AIDS Care and Treatment Programs**

The Health Resources and Services Administration (HRSA) administers the \$2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). NASTAD requests a minimum increase of **\$65.8 million** in FY2016 for state Ryan White Part B grants, including an increase of **\$22.8 million** for Part B and **\$43 million** for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds state health departments to provide care, treatment and support services for low-income

uninsured and underinsured individuals living with HIV. With these funds states and territories provide access to HIV clinicians, life-saving and life-extending therapies and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The state ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare and/or Medicaid.

Throughout and following the ACA implementation, health departments will require capacity-building support in order to create new infrastructure and leverage existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program will continue to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

### **HIV/AIDS Prevention and Surveillance Programs**

NASTAD requests an increase of **\$77 million** in FY2016 for CDC's Division of HIV Prevention. The flagship HIV prevention program, HIV Prevention by Health Departments, funds state and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease in order to see meaningful improvements in individual and community level health outcomes, particularly among disproportionately impacted populations. It is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Unfortunately, only thirty percent of people living with HIV have an undetectable viral load. Addressing interventions along the HIV care continuum is

our newest and most effective tool to get to zero new HIV infections; however, health departments need additional support to successfully implement these strategies.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of point of care information, including CD4 and viral load reporting. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee allow states and localities the discretion to use federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs). Overwhelming scientific evidence has shown SSPs and access to sterile syringes are an evidenced-based and cost-effective means of lowering HIV and hepatitis infection rates, reducing use of illegal drugs and helping connect people to HIV and hepatitis medical treatment, including substance abuse treatment.

### **Viral Hepatitis Prevention Programs**

NASTAD requests an increase of **\$31.5 million** in FY2016 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable state and local health departments to provide the basic, core public health services to combat hepatitis, increase surveillance, testing and education efforts nationwide and effectively implement the recommendations set by the IOM's *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*, the *Action Plan for Viral Hepatitis*, and the CDC and United States Preventive Services Task Force (USPSTF) viral hepatitis testing recommendations for populations with risk factors,

including baby boomers. NASTAD requests that CDC dedicate at least **\$10.5 million** for the viral hepatitis prevention coordinators (VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the *Viral Hepatitis Action Plan*, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to state and local health departments to coordinate prevention and surveillance efforts via the VHPC. For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the hepatitis epidemics. The CDC has estimated that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as much as 75% are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined - a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the FY2016 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against these epidemics.



COALITION OF NORTHEASTERN GOVERNORS

**Statement of the Coalition of Northeastern Governors to the  
Subcommittee on Labor, Health and Human Services, Education,  
and Related Agencies  
Committee on Appropriations  
United States House of Representatives  
Regarding FY2016 Appropriations for the  
Low Income Home Energy Assistance Program (LIHEAP)  
Department of Health and Human Services  
April 6, 2015**

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, Health and Human Services, Education and Related agencies its views regarding the FY2016 appropriations for the Low-Income Home Energy Assistance Program (LIHEAP).

The CONEG Governors appreciate the Subcommittee's long-standing support for this vital program, and recognize the difficult budgetary decisions that face the Subcommittee. In these challenging economic times, the nation's low-income households also face difficult budget choices as they struggle to afford the basic necessity of home energy.

The Governors urge the Subcommittee to fund the LIHEAP program in FY2016 at no less than \$4.7 billion provided as block grants to the states. Adequate, predictable and timely federal funding is essential for LIHEAP to provide a vital lifeline to those households faced with unaffordable home energy bills. The governors also urge the Subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective of addressing the energy burden: "assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs."

In the Northeast and across the nation, LIHEAP assistance is targeted to households with the lowest income and high energy burden. The majority of LIHEAP recipients have incomes far below the eligibility criteria of 150 percent of the federal poverty level (\$23,595 for a two-person household in 2015). More than ninety percent of LIHEAP households have at least one vulnerable member – the elderly or disabled and young children – for whom temperature extremes could have serious health and safety consequences. These low-income households, particularly low-income senior households, spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. The American Association for Retired Persons (AARP) estimates that twenty-seven percent of older households have family incomes of less than \$20,000.

The energy burden of keeping warm and safe is particularly challenging for low-income households in the Northeast which has some of the country's oldest homes and coldest climate. More than any other region of the country, Northeast households are dependent upon delivered

fuels – heating oil, propane and kerosene. In the winter heating season that is just now coming to an end, senior households with incomes of less than \$10,000 heating with fuel oil will spend 14 percent of their income on heating costs. Those heating with other fuels (natural gas, electricity, and propane) can expect to spend between six and nine percent of household income on heating costs.

Although the price of many home heating fuels has remained relatively stable or declined this winter from recent peak prices, the need for the program remains strong. For example, due to this winter's brutal deadly temperatures, low-income families still incurred increased home energy bills. At the end of the heating season, home heating oil prices in the Northeast averaged \$3.00 per gallon according to the Energy Information Administration (EIA). While the need remains great, average LIHEAP benefit levels nationwide have been reduced by almost \$100 since 2010, and the number of households served has declined from 8.1 million in FY2010 to 6.6 million in FY2014.

Reducing home energy costs presents unique challenges to northeast states. Thirty percent of Northeast households rely upon delivered fuels which are also the most expensive and volatile in price. In addition, compared to homes heating with natural gas or electricity, these "delivered fuel" households are less likely to have the option of payment plans, access to utility assistance programs, and the protection of utility service shut-off moratoria during the heating season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

State LIHEAP programs continue to seek innovative and efficient ways to "do more with less" and stretch scarce LIHEAP dollars to ensure that meaningful assistance can be provided to those households with the greatest needs, and as such, benefit from flexibility in the use of block grant funds. State LIHEAP programs, often working with their Weatherization Assistance Programs, help low-income households take steps to reduce their energy use and lower their energy bills. Programs to provide repair or replace inefficient, unsafe and non-working home heating systems improve the safety and reduce the energy use of low-income households. LIHEAP funds are frequently leveraged by utility assistance programs for low-income households. States in the Northeast have worked with utilities to develop payment plans to reduce arrearages and lessen the prospect of utility shut-offs after the heating season ends. They have negotiated with fuel dealers to receive discounts on deliverable fuels, and have entered into agreements to purchase fuel in the summer when prices are lowest. States working to meet the heating and cooling needs of low income households need continued flexibility so that they may allocate limited LIHEAP funding in a manner that best suits their needs.

Even with these programs, many of the lowest income families that benefit from LIHEAP have limited options to reduce their energy bills. There is simply no room in their household budget for energy upgrades. Some older homes and many manufactured homes have structural issues that make them ineligible for weatherization assistance. Low-income families are more likely to rent than to own a home and therefore have less ability or incentive to make significant energy efficiency upgrades to their homes. For many of these households, switching to less expensive heating fuels is simply not possible. Homes in rural and metropolitan areas throughout the



Northeast are not served by natural gas infrastructure. In addition, the New England Fuel Institute estimates that converting a complete home heating system from oil to natural gas can cost as much as \$10,000.

In summary, LIHEAP is targeted to meet the immediate home heating needs of some of the nation's most vulnerable households who face a high energy burden. It is one of the most efficiently run programs with low overhead costs. Even with significant cost-cutting steps, states have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels.

Therefore, the CONEG Governors appreciate the Subcommittee's continued support for LIHEAP, and urge you to fund the core block grant at the level of no less than \$4.7 billion in FY2016.

**Ronald Johnson, Vice President of Policy and Advocacy, AIDS United**

*AIDS United Fiscal Year 2016 Testimony prepared for the  
House Committee on Appropriations Subcommittee on Labor, Health and Human Services,  
Education and Related Agencies*

As the committee begins its important deliberations on the Fiscal Year (FY) 2016 Labor, Health and Human Services, Education and Related Agencies (Labor HHS) appropriation bill, we thank you for your continued commitment to addressing HIV/AIDS in the United States and we ask that you maintain the federal government's commitment to safety net programs that protect the public health. Specifically we ask that you adequately fund *the CDC Division of HIV prevention and surveillance activities at \$822.7 million* to prevent new infections, *AIDS research at the NIH at \$3.6 billion* to find a cure and address other research priorities, *the Ryan White Program at \$2.45 billion* to better ensure that all people living with HIV receive treatment and are retained in care. *We also urge the committee to end the ban on the use of federal funds for syringe exchange* to prevent HIV outbreaks such as the recent outbreak of 79 HIV cases in Indiana.

Unfortunately, due to sequestration and other budget constraints, domestic HIV/AIDS programs and other non-defense discretionary programs have been cut in recent years, even as new HIV infections continue at 50,000 per year and the number of people needing care and treatment increase. For example, since FY2012, the Ryan White HIV/AIDS Program has been cut by \$73 million, HIV prevention at the Centers for Disease Control and Prevention (CDC) has dropped by \$28 million and AIDS research at the National Institutes of Health (NIH) by \$60 million. We are at a time when we can achieve the goals of the National HIV/AIDS Strategy and move towards an AIDS free generation but achievement requires the federal government to continue to commit the necessary resources. We appreciate that the subcommittee has recognized

this need in the past and ask that you continue to increase funding for domestic HIV/AIDS programs as you formulate the FY2016 appropriation measures.

### **The Ryan White HIV/AIDS Program**

Early and reliable access to HIV care and treatment is cost effective and helps people with HIV live healthy and productive lives. Research has found that when people with HIV are on treatment and the virus is suppressed, the chance of HIV transmission is reduced to almost zero. The Ryan White HIV/AIDS Program is a system of care that provides medications, medical care, and essential coverage completion services to approximately 536,000 low-income, uninsured, and underinsured individuals living with HIV/AIDS. With the number of people living with HIV at 1.2 million, the demands on the program, now reaching 60 percent of all people diagnosed with HIV in the U.S., continue to grow while many needs remain unmet.

The Ryan White Program, as a payer of last resort, now works in conjunction with Medicaid, Medicare, and the Affordable Care Act (ACA) to help with out-of-pocket costs and to support access to critical medical and coverage completion services not covered by traditional health insurance. The Ryan White Program also will continue to be the primary source of HIV/AIDS care and treatment for the millions who will not be eligible for health coverage under the ACA, including low-income people who live in non-Medicaid expansion states. Sustained funding of primary care, medications, and coverage completion services in the Ryan White Program continues to be necessary. We urge you to maintain all parts of the program, we also urge you to oppose the Administration's proposal in the FY2016 budget to consolidate Parts C and D, a proposal Congress rejected last year. Such a major change to the program should be made through the reauthorization process. Funding for the Ryan White Program is critical to improving health coverage and outcomes for people living with HIV, therefore, *we urge you to fund the Ryan White Program at a total of \$2.45 billion in FY2016,*

*an increase of \$136 million over FY2015, distributed as follows: Part A, \$687 million; Part B/Care, \$437 million; Part B/ADAP, \$943 million; Part C, \$225 million; Part D, \$85 million; Part F/AETC, \$35 million; Part F/Dental, \$18 million; Part F/SPNS, \$25 million.*

#### **HIV Prevention - CDC HIV Prevention and Surveillance**

Although the United States has significantly reduced the number of infections over 30 years of fighting HIV, there still are 50,000 new infections annually and about 1 in 7 people living with HIV do not know they have the virus. Gay, bisexual, and other men who have sex with men (MSM) continue to be the most impacted by the epidemic and account for 66 percent of all new infections. Between 2008 and 2010, infections among MSM increased by 12 percent, and among MSM aged 13-24 years by 22 percent. Young people, particularly Black and Latino MSM, continue to be the most disproportionately affected by HIV, accounting for one in five new infections in 2012.

AIDS United is pleased that CDC has announced funds targeted to fight HIV among gay, bisexual men and transgender people including funding for a new, effective prevention tool, pre-exposure prophylaxis (PrEP) for MSM and transgender people who are HIV-negative but at substantial risk plus ongoing medical care and antiretroviral treatment for people with HIV. While we are making progress in decreasing new infections among women, black women are still disproportionately affected, accounting for 64 percent of women infected in 2010. Black and Hispanic women ages 13-24 accounted for 82 percent of young women living with HIV in 2010.

Investing in HIV prevention today translates into less spending in the future on care and treatment. We are at a critical juncture in the fight against HIV/AIDS we have the tools to end the epidemic, but we must invest the resources now to bring the vision of an AIDS free generation into reality. In order to achieve the goals of reducing new infections, increasing

knowledge of HIV-positive status, and reducing HIV transmission, funding for the CDC is needed to carry out its High-Impact Prevention activities. ***For FY2016, we request increases of \$67 million over FY2015 for a total of \$822.7 million for the CDC Division of HIV prevention and surveillance activities. [Note: This request does not include the request for DASH]***

### **Access to Sterile Syringes**

Numerous studies have shown that syringe exchange programs (SEP) are a cost-effective means to lower rates of HIV/AIDS and viral hepatitis, do not increase substance abuse (nor the use of illegal drugs) and help connect people to medical treatment, including substance abuse treatment. Unfortunately, prescription opioid addiction has led to a crisis in increased injection drug use with a 75% increase in new hepatitis C infections from 2010-2012 according to the CDC and the first indication of increases in HIV related to injecting drugs. On March 26<sup>th</sup>, Governor Mike Pence of Indiana declared a public health emergency in response to 79 cases of HIV related to injection drug use in 3 months in a county that previously experienced five or fewer cases of HIV in a year. In contrast, when Washington D.C. scaled up its local syringe exchange program, there was an 81% decrease in newly diagnosed HIV cases related to injection drug use. In 2008, the first year of the scale up, there were 109 cases, compared with 21 in 2012.

Syringe exchange, as part of a comprehensive health and prevention program could have helped to prevent the outbreak of HIV in Indiana. SEPs provide comprehensive HIV services, prevention including HIV counseling and testing, reducing sexual and drug use-related health risks, referral to drug addiction treatment, and referral to other medical and social services. Unfortunately, Congress re-imposed a ban on the use federal funds for syringe exchange programs in Fiscal Year 2012 undercutting a potential source of funds for such a program. Ultimately this is a self-defeating policy leading to much higher HIV rates in the U.S.

and a higher cost necessary to respond to the epidemic. For example in Indiana the lifetime cost for treatment alone of these 79 cases of HIV will be more than \$33 million dollars and it's likely that more cases will be found. Most of these cases would have been averted at a much lower cost with syringe exchange. AIDS United strongly urges the committee to end the federal ban on syringe exchange by restoring language to allow local public health or local law enforcement authorities to allow syringe exchange unless such local authorities deem a site to be inappropriate.

### **HIV/AIDS Research at the National Institutes of Health**

Building on recent progress, robust support for HIV research must continue until better, more effective and affordable prevention and treatment regimens—and eventually a cure—are developed and universally available. For the U.S. to maintain its position as the global leader in HIV/AIDS research for the 35 million people globally and 1.2 million people living with HIV in the U.S., we must invest adequate resources in HIV research at the NIH. NIH research has produced promising recent advances, including the study of the prevention effects of treatment, improved treatment programming and the first partially effective HIV vaccine. In order to realize similar breakthroughs in the future and improve the HIV care continuum, continued robust AIDS research funding is essential. *Consistent with the most recent Trans-NIH AIDS Research By-Pass Budget Estimate for FY2013, we ask that you request \$3.6 billion for HIV research at the NIH, an increase of \$600 million over FY2015.*

AIDS United looks forward to a positive outcome for the funding request for HIV/AIDS domestic programs and we thank you for your continued leadership and support of these critical programs for so many people living with HIV, and the organizations and communities that serve them nationwide.



**National League  
for Nursing**

**Testimony Regarding Fiscal Year 2016 Appropriations for the  
Title VIII Nursing Workforce Development Programs  
April 7, 2015**

**Submitted by:** Marsha Adams, PhD, RN, CNE, FAAN, ANEF, President,  
National League for Nursing

Beverly Malone, PhD, RN, FAAN, Chief Executive Officer,  
National League for Nursing

**To:** Subcommittee on Labor, Health & Human Services, Education, and Related Agencies,  
Committee on Appropriations, US House of Representatives

The NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of the nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 26 regional constituent leagues. **The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at \$244 million in FY 2016. This amount is equal to the FY 2010 funding level for the Title VIII programs.**

**NURSING EDUCATION**

Health inequities, inflated costs, and poor health care outcomes are intensifying because of today's shortfall of appropriately prepared registered nurses (RNs) and licensed vocational/practical nurses (LVN/LPNs). With 4.5 million active, licensed RNs/LPNs, nurses are the primary professionals delivering quality health care in the nation. According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 19.4 percent from 2012 to 2022, resulting in 1,052,600 job openings due to growth and replacement needs. BLS also calculates the LVN/LPN workforce will grow by 25 percent resulting in 363,100 job openings during the same timeframe. This increase is fueled by technological advancements for treatments, preventive care needs, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year. The situation is further affected by the needed replacement of some

526,800 jobs vacated by RNs and 182,900 vacated by LVN/LPNs who will leave the profession and/or retire by 2022.

The nursing shortage continues to outpace the level of federal resources allocated by Congress to help alleviate it. Appropriations for nursing education are inconsistent with the health care reality facing our nation today. For the last 50 years, the Title VIII nursing workforce development programs have provided training for entry-level and advanced practice registered nurses (APRNs) to improve the access to, and quality of, health care in underserved communities. The Title VIII programs are fundamental to the infrastructure delivering quality, cost-effective health care. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. Insufficient federal investments in the nursing workforce are a short-sighted course of action that further jeopardizes access to, and the quality of, the nation's health care delivery. Absent consistent support, slight boosts to Title VIII programs will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

#### **THE NURSE PIPELINE AND EDUCATION CAPACITY**

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and states. As the United States tackles the workforce shortage that exacerbates the stress in the health care system, nursing programs across the country are rejecting qualified candidates because there is not enough faculty to teach them. Sixty-four percent of all nursing programs turn away qualified applicants. Pre-licensure nursing programs — which serve as the gateway into the nursing workforce — reject 72 percent of qualified applicants due to limited space. NLN research on America's nearly 60,000 nurse educators shows that a core cause of the shortage is an aging and over-worked faculty who earn less than nurses entering clinical practice. Sixty percent of all full-time nurse faculty



members are 45- to 60-years old. Fifty-five percent of nurse faculty say they are likely to leave academic nursing by 2020. BLS projects a need of 35 percent more faculty members to meet the expected increase in demand. In addition, with 10,200 current faculty members expected to retire, 34,200 new nursing instructors will be needed by 2022.

#### **EQUALLY PRESSING IS LACK OF DIVERSITY**

Besides representing an untapped talent pool to remedy the nationwide nursing shortage, diversity in nursing is essential to developing a health care system that understands and addresses the needs of our rapidly changing population. Our nation is enriched by cultural complexity – 37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 26 percent of the student population and males only 16 percent of pre-licensure RN students. A survey of nurse educators conducted by the NLN and the Carnegie Foundation's Preparation for the Professions Program found that only 7 percent of nurse educators were minorities compared with 16 percent of all U.S. faculty. The lack of faculty diversity limits nursing schools' ability to deliver culturally appropriate health professions education. Workforce diversity is needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

#### **TITLE VIII FEDERAL FUNDING REALITY**

Today's undersupply of appropriately prepared nurses and nurse faculty, as well as the projected loss of experienced nurses over the next decade, does not bode well for our nation. The Title VIII nursing workforce development programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, loans, scholarships, and services that enable

students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below provide a perspective on current federal investments.

The **Advanced Nursing Education (ANE)** program supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, nurse practitioners, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In FY 2013, ANE program grantees trained 10,504 nursing students and produced 2,475 graduates. In addition, 36 percent of students trained were underrepresented minorities and/or from disadvantaged backgrounds.

**Nursing Workforce Diversity (NWD)** grants increase educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In FY 2013, the number of nursing program students trained was 6,691. Additionally, 2,419 nursing students graduated from nursing programs and program grantees provided scholarships to 1,416 students.

**Nurse Education, Practice, Quality, and Retention Grants (NEPQR)** address the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. The NEPQR program trained more than 1,289 BSN students in FY 2013. The NEPQR program funded the Veterans' Bachelor of Science in Nursing (VBSN) program for the first time in FY 2013 and made awards to nine schools. Forty-five veterans were enrolled in BSN degree programs and five graduated with a BSN degree. It is estimated that 42 percent of participating veterans were underrepresented minorities in the field of nursing, and 56 percent reported coming from a financially and/or educationally disadvantaged background. Lastly, the NEPQR program funded several Nurse Managed Health Clinics (NMHC) with the primary purpose of creating infrastructure and serving as clinical training sites for students across the health professions. It is estimated that more than 900 health professions students were trained because of these activities.

The **Nurse Faculty Loan Program (NFLP)** supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. In FY 2013, the NFLP supported 2,401 students pursuing faculty preparation. Seventeen percent of students who received a loan reported coming from a disadvantaged background and about one out of every four students receiving the NFLP loans were underrepresented minorities.

The **Comprehensive Geriatric Education Program (CGEP)** provides support to educate individuals in providing geriatric care for the elderly. This goal is accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees. In FY 2013, CGEP grantees awarded traineeships to 77. A majority of students received clinical training in a medically underserved community (62 percent) and/or a primary care setting (74 percent).

The **NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)** offers to individuals, who are enrolled or accepted for enrollment as full-time or part-time nursing students, the opportunity to apply for funds. The NURSE Corps repays up to 85 percent of nursing student loans in return for at least three years of practice in a designated nursing shortage area. In FY 2014, the NURSE Corps loan repayment program made 667 loan repayment awards and 412 continuation awards. The NURSE Corps scholarship program made 242 new scholarship awards and 13 continuation awards during the same time period.

***The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at the FY 2010 funding level of \$244 million in FY 2016.***

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**RAILROAD RETIREMENT BOARD  
OFFICE OF INSPECTOR GENERAL  
FISCAL YEAR 2016 BUDGET REQUEST**

**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES OF THE  
COMMITTEE ON APPROPRIATIONS  
U.S. HOUSE OF REPRESENTATIVES**

**MARTIN J. DICKMAN, INSPECTOR GENERAL**  
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**STATEMENT FOR THE RECORD**

**April 29, 2015**

Mr. Chairman and Members of the Subcommittee:

My name is Martin J. Dickman, and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

**BUDGET REQUEST**

The President's proposed budget for Fiscal Year (FY) 2016 would provide \$9,450,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During FY 2016, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

## **OPERATIONAL COMPONENTS**

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and five domicile investigative offices located in Virginia, Texas, California, Florida, and New York. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies, with which the OIG works joint investigations.

### **OFFICE OF AUDIT**

The mission of the Office of Audit (OA) is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During FY 2016, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified six broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act Benefit Program Operations; RRB Contracts and Contracting Activities; Railroad Medicare Program Operations; Security, Privacy, and

Information Management; and Improper Payments Act of 2010 Oversight. OA must also accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002, evaluation of information security pursuant to the Federal Information Security Management Act (FISMA), audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010, review of IG Requirements for Government Charge Card Abuse and Prevention Act of 2012, and Identification of Performance and Management Challenges for FY 2016.

During FY 2016, OA will complete the audit of the RRB's FY 2015 financial statements and begin its audit of the agency's FY 2016 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in FY 2006. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, and Congressional and Presidential concerns.

## OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

### OI Investigative Results for FY 2014

<u>Civil Judgments</u>	<u>Indictments/Informations</u>	<u>Convictions</u>	<u>Recoveries/Receivables</u>
24	35	89	\$343,500,000 <u>1/</u>

OI anticipates an ongoing caseload of about 400 investigations in FY 2016. During FY 2014, OI opened 184 new cases and closed 236. At present, OI has cases open in 48 states, the District of Columbia, and Canada with estimated fraud losses of over \$401 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

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1/ This total amount of financial accomplishments reflect fraud amounts related to programs administered exclusively by the RRB and fraud amounts from other Federal Programs such as Medicare or Social Security, which were included in the disposition resulting from the investigation.

Of particular significance is an ongoing disability fraud investigation in New York. To date, 33 individuals have been indicted; 28 of these have pleaded guilty and five more were convicted in Federal court. All individuals prosecuted in connection with this case have been sentenced. In addition, 44 former railroad employees avoided prosecution by admitting their role in the fraud and agreeing to the termination of their benefits. OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in FY 2016.

During FY 2016, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

### **CONCLUSION**

In FY 2016, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.



**Public Witness Testimony of Jill Kagan, Chair, National Respite Coalition  
For the House Subcommittee on Labor, HHS and Education Appropriations  
In support of funding for the Lifespan Respite Care Program  
Administration for Community Living, Dept. of Health and Human Services  
April 8, 2015**

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of state respite coalitions, respite providers, family caregivers, and national, state and local organizations that support respite. The NRC is **requesting that the Subcommittee include \$5.0 million for the Lifespan Respite Care Program in the FY 2016 Labor, HHS, and Education Appropriations bill as recommended in the President's FY 2016 budget.** This will enable:

- State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite.
- Improvement in respite quality and expansion of respite capacity; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

***Who Needs Respite?*** A 2013 Pew Research Center survey found that 40% of adults in the U.S. are caring for an adult or child with significant health issues, up from 30% in 2010 (*Fox, et al, 2013*). A new RAND Corporation study estimates the value of caregiving in the US by friends and relatives of the aging at \$522 billion a year. Replacing that care with unskilled paid care would cost \$221 billion, while replacing it with skilled nursing care would cost \$642 billion annually (*Chari, et al., 2014*). The value of caregiving increases by \$100 billion when caregivers of younger persons are included. Caregiving is a lifespan issue with the **majority** of family caregivers caring for someone **under age 75 (56%)** (*National Alliance for Caregiving (NAC) and AARP, 2009*).

National, State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers (*The Arc, 2011; National Family Caregivers Association, 2011*). ***Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer. Yet, nearly 90% of family caregivers across the lifespan are not receiving respite services at all (NAC and AARP, 2009).***

A 2014 report prepared by the Rand Corporation for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that respite care should be more widely available to military caregivers (*Ramchand, et al., 2014*). The Dole Foundation's Respite Impact Council found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

An estimated 80% of all long-term care in the U.S. is provided at home. This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living with their aging parents, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

***Respite Barriers and the Effect on Family Caregivers.*** Barriers to accessing respite include fragmented services, cost, a critically short supply of well-trained respite providers, and lack of information about respite. Lifespan Respite is designed to help states eliminate these barriers through improved coordination and capacity building.

While most families want to care for family members at home, research shows that family caregivers are at risk for serious emotional, mental, and physical health problems (*Family Caregiver Alliance, 2006*). When caregivers lack effective coping styles or are depressed, care

recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health (*American Psychological Association, nd*).

Supports that would ease family caregiver stress, most importantly respite, are too often out of reach or completely unavailable. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%), yet more than 75% could not find respite (*The Arc, 2011*). Respite may not exist at all for those with Alzheimer's, with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions or autism.

***Respite Benefits Families, Government, and Businesses through Cost Savings.*** Respite has been shown to reduce stress and improve family caregiver health and well-being. In turn, respite helps avoid or delay out-of-home placements, minimizes risk of abuse and neglect, and strengthens family stability. A study of parents of children with autism found that respite was associated with improved marital quality (*Harper, Amber, et al, 2013*). A US Dept of Health and Human Services study found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (*Spillman and Long, 2007*). In a survey of caregivers of adults with MS, two-thirds said respite would help keep their loved one at home (*NAC, 2012*).

Budgetary benefits accrue because of respite. Delaying a nursing home placement for one person with Alzheimer's can save Medicaid and other government programs thousands of dollars. University of Pennsylvania researchers studied the records of 28,000 children with

autism enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite, there was an 8% drop in the odds of hospitalization (*Mandell, et al, 2012*). In the private sector, U.S. businesses lose from \$17.1 to \$33.6 billion per year in lost productivity of family caregivers (*MetLife Mature Market Institute, 2006*). Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (*Witters, 2011*). Respite for working family caregivers could improve job performance, saving employers billions.

***Lifespan Respite Care Program Helps.*** The federal Lifespan Respite program administered by the Administration for Community Living (ACL) provides competitive grants to eligible state agencies. Congress appropriated \$2.5 million each year from FY09 - FY12 and slightly less in FY13-FY15. Since 2009, 32 states and DC have received Lifespan Respite Grants. States are required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in accessing respite. Lifespan Respite helps states maximize use of limited resources across age and disability groups and deliver services more efficiently. Increasing funding, even slightly, in FY 16 could allow funding of several new states and help assist the remaining grantees to complete the important and ground-breaking work that they have started.

***How is Lifespan Respite Program Making a Difference?*** With limited funds, Lifespan Respite grantees are engaged in innovative activities:

- In TN and RI, the Lifespan Respite programs are expanding volunteer networks of respite providers by recruiting university students or Senior Corps volunteers.

- In AL and SC, state respite coalitions are partnering with the untapped faith community to provide respite, especially in rural areas.
- The NC grantee partnered with the Money Follows the Person program to develop family caregiver peer-to-peer support and respite.
- In NH, new respite providers have been trained through partnerships with the state labor division, NH National Alliance on Mental Illness, NH Family Voices, and others.

Additional partnerships between state agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with the state's Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the state's Transit Administration to develop mobile respite to serve isolated rural areas of the state. States are building respite registries and "no wrong door systems" to help family caregivers access respite and funding sources. AL, NC, NV, OK, RI, SC, TN, WA and others are implementing consumer-directed respite so that family caregivers can pay for respite and select their own providers. States are developing comprehensive sustainability plans, but without federal support, many of the grantees will be cut off before these initiatives achieve their full impact.

No other federal program has respite as its sole focus, helps ensure respite quality or choice, and allows respite start-up, training or coordination. We urge you to include \$5 million in the FY 16 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.

***Complete references available upon request. National Respite Coalition,***

***[www.archrespite.org](http://www.archrespite.org)***

**Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education Concerning Programs in the United States Departments of Labor, Health and Human Services, and Education**

**By**  
**Corporation for Supportive Housing**  
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April 9, 2015

The Corporation for Supportive Housing (CSH) is a nonpartisan, nonprofit organization helping communities develop supportive housing (SH) and reorient systems to improve resource allocation to create and sustain evidence-based solutions. We have offices in 12 states (California, Arizona, Texas, Illinois, Indiana, Ohio, Minnesota, Michigan, New York, Georgia, and Connecticut) and the District of Columbia and have a presence in several others. Supportive housing is affordable housing combined with stabilizing services to help families and individuals address their disabling conditions while living in safe apartments. CSH has helped communities create and develop supportive housing for populations with substance use addiction, mental health illness, chronic diseases, involvement with child welfare, exiting the criminal justice system and homeless young adults.

Supportive housing providers receive a portion of the funds necessary to build or secure affordable housing from the Department of Housing and Urban Development (HUD) or state housing resources. There is also a need for the Department of Health and Human Services (HHS) to ensure that resources are available for services such as case management, landlord negotiation, connection to health services, counseling and medication management. Providers often use a combination of state, local, foundation and privately raised funds to pay for the vital social services chronically homeless populations may need to stay housed. Increasingly, organizations are able to access Medicaid to provide services when the service is part of the benefit package for a household and the provider is licensed to bill Medicaid. In order to build the housing units needed to end homelessness, serve those leaving institutional care, help families with children stay together and afford homeless transition age youth, the Department of Health and Human Services must increase its investment in services that are paired with housing programs. To this end, CSH recommends the following:

- **Allocate \$100 million** for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.
- **Increase** funding for the Projects for Assistance in Transition from Homelessness (PATH) program to **\$75 million**, the fully authorized level.
- Increase funding for the Runaway and Homeless Youth Act Programs to **\$165 million**, its authorized funding level.
- Provide **\$1.5 billion** in the discretionary Community Health Center program and \$3.6 billion in Affordable Care Act mandatory funding, both are located within the Health Resource Services Administration. This would result in **\$447.3 million** for the Health Care for the Homeless program.

- Provide **\$80 million** for the Social Innovation Fund (SIF) program in the Corporation for National and Community Service.

## Background

While HUD has made significant housing investments, there is a need for HHS to increase its role in providing services resources for organizations to create supportive housing. A supportive housing residents live with serious mental illness, substance use disorders or chronic health conditions and to retain housing must have access services that require HHS resources.

We know supportive housing works. Over 80 percent of residents remain housed after the first year. In addition, work CSH has done targeting frequent users of health, jails or prisons illustrates the cost effectiveness of supportive housing. In California, we implemented the Frequent Users of Health Services Initiative (FUHSI). Through this study, we found that by placing clients into supportive housing we reduced their emergency room costs by 59 percent, reduced their inpatient days by an average of 62 percent and reduced average inpatient charges by 69 percent.

Our project targeting frequent users of jails and prisons has shown similar results. In New York, CSH's Frequent Users of Services Enhancement (FUSE) Initiative was a joint project between the New York City Departments of Corrections and Homeless Services with assistance from the Department of Health and Mental Hygiene and the New York City Housing Authority. By assisting ex-offenders and providing supportive housing to those who need it, NYC was able to help clients reduce jail stays by 33 percent and reduce mental health stays by 18 percent. For the 86 people served, the FUSE initiative was able to offset over \$3,500 in either jail or mental health costs per client.

In addition, there are several other subpopulations experiencing either homelessness or housing instability that would benefit from increased social services oriented funding. On a small scale, SAMHSA programs have targeted youth, veterans and families to ensure that all people who could benefit from mental health and substance use treatment can receive specialized support. However, without increased funding, communities will not be able to fully implement the supportive housing model for the hundreds of thousands of people who can benefit from it.

## Detailed Program Descriptions

### **SAMHSA Support Services for Supportive Housing Projects**

*CSH recommends allocating \$100 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.*

Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past three years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase funding for services to help those populations address their long-term health related issues.

### **Projects for Assistance in Transition from Homelessness (PATH)**

*CSH recommends that Congress increase PATH funding to \$75 million and adjust the funding formula to increase allocations for small states and territories.*

PATH provides outreach to eligible consumers and ensures that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid, and welfare programs. PATH supported programs served over 181,537 people through outreach in fiscal year 2013. Of those for whom a diagnosis was reported, approximately 66 percent were receiving community mental health services and 56 percent had co-occurring substance use disorders.

One issue that needs consideration, under the PATH formula grant, approximately 30 states share in the program's annual appropriations increases. The remaining states and territories receive the minimum grant of \$300,000 for states and \$50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to \$600,000 for states and \$100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

### **Community Health Centers and Health Care for the Homeless (HCH) Programs**

*CSH recommends \$1.5 billion in the discretionary Community Health Center program and \$3.6 billion in Affordable Care Act mandatory funding for community health centers. This would result in \$447.3 million for the Health Care for the Homeless program.*

Persons living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, and heatstroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.<sup>1</sup> Health care for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7% of the Consolidated Health Centers account for HCH projects.

### **Runaway and Homeless Youth Program**

*CSH recommends \$165 million for the Runaway and Homeless Youth (RHYA) Act Programs. RHYA programs are dedicated to reaching homeless youth. RHYA funding goes towards outreach to youth living on the street, emergency shelters and transitional housing programs. CSH recommends including a Pay for Success Initiative in the RHYA account to test models that serve high-need youth, such as those with disabling conditions or those who have had multiple placements in out-of-home care. A Pay for Success Model could braid funding from RHYA, HUD and Title IV-E to fund supportive services for this target population.*

On any given night, approximately 46,000 youth are homeless. Homeless youth leave their current homes for many reasons, including physical abuse, sexual abuse, extreme poverty or other trauma. Unfortunately, less than 5,000 youth are able to access stable housing resources each year. RHYA is the only dedicated resource that is made available to serve this population. Increasing funding for the three core programs is critical to reduce the number of youth living on the streets. Further, a Pay for Success program that targets

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<sup>1</sup> Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. *Physical Health, Mental Health and Substance Abuse Problems of Shelter Users*. Health and Social Work, Vol. 19, 1994



youth with higher needs will allow providers to blend different models to achieve positive outcomes for youth.

### **Child Abuse and Prevention Treatment Act (CAPTA)**

*CSH recommends funding the Administration request for CAPTA but include an additional \$20 million funding for services for families or eligible youth receiving Family Unification vouchers. The Administration requested \$20 million for Family Unification vouchers that assist families involved with child welfare or youth exiting foster care.*

The Child Abuse and Prevention Treatment grants are dedicated to the prevention, assessment, identification and treatment of child abuse and neglect. Currently, ACF is using discretionary grants to fund the Partnerships to Demonstrate the Effectiveness of Supportive Housing for Families with Child Welfare Involvement that connects housing and services to create a program that focuses on both family preservation and reunification, reduce out-of-home care and ultimately end cycles of involvement with child welfare. Through this demonstration, services and case management have played a critical role in family stability and reducing time in out of home care for children of homeless families. CSH recommends an additional \$20 million in CAPTA discretionary grants to allow ACF to attach services and case management to Family Unification vouchers that serve families involved with child welfare or youth exiting foster care.

### **Social Innovation Fund, CNCS**

*CSH recommends providing \$80 million for the Social Innovation Fund (SIF) at CNCS and 20% of the funding be set aside for Pay for Success Initiatives.*

CSH is actively involved with Social Innovation Fund projects and Pay for Success projects that are geared towards reducing health care costs for homeless populations that are high utilizers of emergency healthcare systems. Through the Social Innovation Fund initiative, CSH is working with four organizations to implement an integrated supportive housing model that incorporates care management to help households address behavioral and physical health conditions while reducing costs. In addition, CSH recently received a Pay for Success grant to help strengthen the supportive housing creation pipeline, using the Pay for Success grant, nonprofit community-based providers will create evidence based programs that are aimed at helping low-income families overcome challenges and improve economic opportunities and healthy outcomes.

### **Conclusion**

As communities implement plans to end homelessness, work to move people out of institutional care and seek to end the cycle of over using public systems, they are struggling to find funding for the services that vulnerable populations need to maintain housing. The federal investments in mental health services, substance abuse treatment, primary care, youth housing, and case management discussed above will help communities create stable housing programs and change social systems which will prevent and end homelessness for millions of Americans.

**The Ovarian Cancer National Alliance**  
**House Committee on Appropriations Subcommittee on**  
**Labor, Health and Human Services, Education and Related Agencies**  
**Written Testimony for the Record**

**Contact information:**

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Laura Koontz, Ph.D.  
Director of Policy  
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The Ovarian Cancer National Alliance (the Alliance) greatly appreciates the opportunity to submit testimony for the record regarding our fiscal year (FY) 2016 funding recommendations. The FY 2016 programmatic funding levels we are advocating for will help advance the awareness, detection, and treatment of ovarian cancer, the deadliest of gynecologic cancers. Specifically, the Alliance respectfully requests Congress provide **\$7.5 million for the Center for Disease Control and Prevention’s (CDC) Ovarian Cancer program.** The CDC-led public gynecologic cancer (ovarian, uterine, cervical, vaginal, vulvar) awareness initiatives authorized by Johanna’s Law play an integral role in women’s cancer education, detection, and prevention. As such, the Alliance respectfully requests Congress appropriate **\$5.5 million for Johanna’s Law implementation.** Furthermore, to advance and leverage the important ovarian cancer research funded through the National Cancer Institute (NCI) at the National Institutes of Health (NIH), the Alliance respectfully requests Congress allocate **\$5.4 billion to NCI, as a portion of \$33 billion appropriated to NIH in FY 2016.**

For 18 years, the Alliance has worked to increase awareness of ovarian cancer and advocate for federal investment in research leading to new diagnostics and more effective treatments. As an umbrella organization of 60 state and regional partner member organizations, the Alliance unites the efforts of survivors, caretakers, and health care professionals to bring national attention to ovarian cancer. To advance the interests of women with ovarian cancer, the Alliance advocates at a national level for greater investment in federal research to support the development of an early detection test, improved health care practices and life-saving treatment protocols. The Alliance also educates health care professionals about – and raises public awareness of – the risks and symptoms of ovarian cancer.

Ovarian cancer is a highly deadly disease. According to the American Cancer Society, in 2015, an estimated 21,290 women will be diagnosed with ovarian cancer and 14,180 women will lose their lives to this terrible disease. A quarter of women diagnosed with ovarian cancer will die within one year of diagnosis and over half of women do not survive five years after diagnosis. Unfortunately, these rates have not changed in nearly 40 years. These grim statistics arise from the fact that there is no early detection test for ovarian cancer; tragically, most cases of ovarian cancer are diagnosed after the disease has already begun to spread and are more difficult to treat effectively. However, if ovarian cancer is caught in the early stages, nearly ninety percent of women survive. As such, it is critical that women and health care providers be aware of the signs and symptoms of ovarian cancer and that valid and reliable early detection tests be developed.

In 2014, the first drugs in 16 years were approved by the Food and Drug Administration (FDA) for ovarian cancer, but are only available to a small percentage of ovarian cancer

patients. Many FDA approved drugs available to all patients are platinum-based therapies, to which cancers readily become resistant if multiple rounds of chemotherapy are needed. Greater than seventy percent of ovarian cancer patients will have a recurrence of disease, underscoring the great need for new and better treatments for ovarian cancer.

For these reasons, we respectfully urge you and your colleagues to support ovarian cancer research, education, and awareness efforts.

#### **CDC Division of Cancer Prevention and Control - Ovarian Cancer**

The Ovarian Cancer Line (also known as the Ovarian Cancer Control Initiative) funds public health research of ovarian cancer to better identify women most at risk for developing ovarian cancer, and design risk-reduction and prevention-focused interventions. In FY 2015, CDC's Ovarian Cancer program received \$7.0 million to achieve its mission. Some of the projects being supported by those funds include the development of a Continuing Medical Education curriculum on hereditary breast and ovarian cancer to educate physicians about how to identify, screen, and manage high-risk patients; the creation of the *Know:BRCA*, a web-tool for evaluating a woman's risk of heredity breast and ovarian cancer; and the examination of treatment disparities, risk factors, and other influences on survival rates to help identify ways to improve patient outcomes with existing tools and treatments.

With an allocation of \$7.5 million in FY 2016, CDC will be able to continue its important public health research, but also expand a pilot initiative integrating ovarian cancer risk assessment, education, and genetic testing into its other cancer-related programs, such as the EARLY Act. Given the shared risk between ovarian and breast cancers for individuals with *BRCA*

mutations, integrating breast and ovarian cancer programs in this manner will leverage scarce resources, better coordinate efforts between existing federal programs, create economies of scale and efficiencies with respect to CDC education and awareness programs, and advance complementary efforts to reduce ovarian cancer related deaths.

#### **CDC Division of Cancer Prevention and Control – Johanna’s Law**

Johanna’s Law funds a CDC-led gynecologic cancer awareness campaign, *Inside Knowledge*, which educates women and health care providers about the signs and symptoms of gynecologic cancers. In FY 2015, CDC received \$5.5 million for Johanna’s Law activities, which include supporting the ongoing creation and dissemination of patient and health care provider awareness campaign materials in English and Spanish and a series of print, radio and television PSAs featuring survivor stories. In 2012, the campaign achieved 1 billion views of its PSAs across media types.

With steady funding in FY 2016, CDC will be able to continue to raise awareness of the signs and symptoms of ovarian and other gynecologic cancers, undertake a targeted outreach of its messages to those women with particular disease risk factors, and expand its partnerships with external patient advocacy, health professional, and other stakeholder organizations to leverage scarce resources and amplify their messages.

#### **NCI at NIH**

NCI and the NIH fund the majority of ovarian cancer research in the United States and the world. On average, each year, NCI and NIH fund more than \$130 million in peer-reviewed,

research grants to researchers at universities and small businesses across the United States. These studies are generating insights into the origins of ovarian cancer and disease progression that help lead to the development of early detection tests and better treatments for ovarian cancer. For example, NIH and NCI investments in basic research led to the understanding of a class of enzymes called PARPs implicated in ovarian cancer. Pharmaceutical companies have built upon these insights to develop PARP inhibitors, the first of which was approved for ovarian cancer in 2014.

In addition to the basic research underlying future cures, NCI supports clinical research necessary for translating those ideas into treatments. NCI funding provides critical support to the ovarian cancer Specialized Programs of Research Excellence (SPORES), which facilitate collaborative research studies on the early detection and treatment of ovarian cancer. NCI's clinical trials enterprise, the National Clinical Trials Network plays an essential role in testing the safety and effectiveness of potential treatments for ovarian cancer.

Robust investment in NCI of \$5.4 billion, out of a total \$33 billion for NIH in FY 2016, is critical to ensuring the next generation of discoveries that will improve the health and well-being of women with – and at-risk for ovarian cancer – as well as all Americans.

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The Alliance maintains a long-standing commitment to working with Congress and other stakeholders to improve the survival rates for women with ovarian cancer through increased research, education and awareness. On behalf of our community of patients, caregivers, and survivors, we thank you for your consideration of our FY 2016 requests and urge you to support the aforementioned federal programs so vital to conquering this horrible disease.

**Submitted by Mary M. Langman, Director, Information Issues and Policy, Medical Library Association**

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) request \$394,090,000 for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), in FY 16. Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available to all who need it. As health sciences librarians who use NLM's programs and services every day, we can attest that these resources literally save lives, making NLM an investment in good health.

**NLM Leverages NIH Investments in Biomedical Research.** We thank the Subcommittee for its long-time commitment to strengthen NLM's budget. The budget supports services that sustain the nation's biomedical research enterprise and more—it builds, sustains, and augments NLM's suite of more than 200 databases which provide information access to health professionals, researchers, educators, and the public. It supports library operations including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium. In FY16 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data.

NLM maximizes the return on the investment in NIH-funded research. It makes the results of biomedical information accessible to researchers, clinicians, business innovators, and the public, enabling data and information to be used more efficiently and effectively to drive innovation and improve health. A leader in Big Data, NLM helps accelerate deployment of health information technology, including electronic health records (EHRs), by leading the

development, maintenance and dissemination of key standards for health data interchange now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through expansion of its clinical trial registry and results database (ClinicalTrials.gov), and to the nation's ability to prepare for and respond to disasters.

**Growing Demand for NLM's Basic Services.** NLM delivers more than a trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the nation use NLM's services to help clinicians, students, researchers, and the public access information they need to save lives and improve health. Without NLM, our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services (e.g., GenBank, PubMed, and PubMed Central) are revolutionizing medicine and ushering in an era of personalized medicine where care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. PubMed, with more than 24 million citations to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 765,000 new citations were added in FY15, and the database provided high quality medical information to about 2 million users each day. PubMed Central is a digital archive which provides public access to the full-text versions of more than 3.3 million biomedical journal articles. On a typical weekday more than one million users download 1.65 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.



As the world's largest, most comprehensive medical library, NLM's print and electronic collections increase annually, and contain more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

**Encourage NLM Partnerships.** NLM's outreach programs are essential to MLA and AAHSL. Through the National Network of Libraries of Medicine (NN/LM), with over 6,300 members in communities nationwide, these programs train medical librarians, health professionals and the general public in the effective use of NLM's services. The NN/LM promotes educational outreach for public libraries, secondary schools, senior centers and other consumer settings, and its outreach programs to underserved populations reduces health disparities among large sections of the American public. NLM's Partners in Information Access program improves access by local public health officials to information which prevents, identifies and responds to public health threats and provides electronic health information services that protect public health.

MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish, and has become a top destination for those seeking information on the Internet, attracting more than 1.6 million visitors daily. Recently, selected materials have made available in forty other languages, and new versions of MedlinePlus and MedlinePlus en español have been optimized for easier use on mobile phones and tablets. Other public health and wellness products and services include the *NIH MedlinePlus Magazine* and *NIH MedlinePlus Salud*, available in doctors' offices nationwide, and NLM's MedlinePlus

Connect, which enables clinical care organizations to implement links from their electronic health records systems to patient education materials in MedlinePlus.

**Emergency Preparedness and Response.** Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM's Disaster Information Specialization (DIS) builds the capacity of librarians and other interested professionals to provide disaster-related health information outreach. NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters.

**Health Information Technology and Bioinformatics.** NLM supports informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support. NLM partners with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools that make it easier for EHR developers and users to implement accepted health data standards in their systems and link to relevant patient education materials.

**Dissemination of Clinical Trial Information.** We applaud the NIH and NLM for their efforts to expand and clarify regulations for clinical trials registration and results submission. These efforts will enhance the transparency of clinical trial results, and provide patients with more information to make necessary health care decisions, including critical information about the safety of products and treatment options. Clinicians will have access to results information about efficacy, adverse effects, and safety; and biomedical researchers will have information on research design, safety, and scientific results that can inform future protocols and discoveries.

**Improving Public Access to Funded Research Results.** Earlier this year, the Department of Health and Human Services (DHHS) announced its plans and common policy approach to expanding public access to the results of scientific research funded by HHS agencies. Its operating divisions will utilize NLM's PubMed Central as the common repository for its peer-reviewed publications and PubMed, a repository of citations, for the sharing of metadata. NLM's experience in developing these systems and related tools and engaging the health sciences library community in outreach will be essential to effective implementation of HSS-wide policies and improving compliance.

Thank you again for the opportunity to present our views. As health sciences librarians who use NLM's products and services and as intermediaries who provide services to researchers, clinicians, and the public, we value and rely upon the high quality invaluable support and leadership that NLM provides in support of our nation's health professionals, educators, researchers, and the public.

**Organizational Bios**

The Medical Library Association (MLA) is a nonprofit, educational organization with 3,700 health sciences information individual and institutional members. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a network of partners to promote the importance of quality information for improved health to the health care community and the public.

The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management. AAHSL membership is composed of 166 academic health sciences libraries whose medical schools hold member or associate member status in the Association of American Medical Colleges.



American  
Dental  
Hygienists'  
Association

**Written Testimony of Kelli Swanson Jaecks, MA, RDH**

**President, American Dental Hygienists' Association**

**On FY 2016 Appropriations for the Department of Health and Human Services Impacting Oral Health**

Submitted to the

**Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
United States House of Representatives**

The Honorable Harold Rogers, Appropriations Committee Chair

The Honorable Nita Lowey, Appropriations Committee Ranking Member

The Honorable Tom Cole, Subcommittee Chair

The Honorable Steve Womack, Subcommittee Vice Chair

The Honorable Rosa DeLauro, Subcommittee Ranking Member

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#### **Introduction**

On behalf of the American Dental Hygienists' Association (ADHA), thank you for the

opportunity to submit testimony regarding FY 2016 appropriations. For all of the reasons

enumerated below, **ADHA urges \$2 million in FY 2016 funding for HRSA's dental workforce**

**demonstration projects, Section 340G-1 of the Public Health Service Act.** Oral health is a part

of total health and Section 340G-1 and other authorized oral health care programs require

appropriations support in order to increase the accessibility of oral health services, particularly

for the underserved. **Given the nation's oral health access crisis, the dearth of dentists**

**serving vulnerable populations and the widespread calls for new types of dental providers,**

**ADHA requests that the Subcommittee reconsider its persistent block on funding for Section**

**340G-1 of the Public Health Service Act – a much-needed dental workforce demonstration**

**program. Specifically, ADHA asks that an evidence-based decision be made with respect to**

**the funding prohibition.** Lifting the block on these dental workforce grants, officially titled the

Alternative Dental Health Care Providers Demonstration Program, would send an important signal to states and to HRSA that innovation in dental workforce is a meritorious undertaking. Even lifting the block and *not* funding the program would be a positive message to states. Importantly, the authorizing language requires that the grants be conducted in compliance with state law, that they must increase access to dental health care in rural and other underserved communities, and that the Institute of Medicine provide a qualitative and quantitative evaluation of the grants. **Nothing in Section 340 G-1 would enable oral health practitioners to perform dental surgery or “irreversible procedures,” unless a state specifically allowed such services.** Further, because the authorizing language requires HRSA to begin the dental workforce grants under Section 340G-1 within two years of its 2010 enactment (i.e., by 2012) and to conclude it within seven years of enactment (2017), language directing HRSA to move forward with Section 340G-1 grants despite this timeline is needed.

#### **Widespread Support for Dental Workforce Innovation**

The American Dental Association (ADA), ADHA and numerous other groups have called for the creation of new types of dental providers. Innovative oral health practitioner models were authorized in Minnesota in 2009, followed by Maine in 2014. A February 2014 Report to the Minnesota Legislature on the early impact of the new providers found that benefits include “direct cost savings, increased dental team productivity, improved patient satisfaction and lower appointment fail rates.”<sup>1</sup> Several states are considering mid-level oral health practitioner legislation. Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in state efforts to increase oral health care access by adding new types of dental providers to the dental team. Groups as disparate as Families USA and Americans for

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<sup>1</sup> <http://www.health.state.mn.us/divs/orhpc/workforce/dt/dtlegrspt.pdf>

Prosperity have called for exploration of new dental providers. Families USA called for “improving access to care through greater use of mid-level providers such as nurse practitioners and dental therapists”<sup>2</sup> and Americans for Prosperity wrote in January 2015 that states should be “free to innovate” in the dental workforce to solve access issues. The National Dental Association, representing 6,000 Black dentists, issued its “Position on Access to Care and Emerging Workforce Models,” which noted that NDA “supports the development and continuation of demonstration projects that can demonstrate the impact and effectiveness of Emerging Workforce Models [expanded function dental hygienists, expanded function dental assistants, or dental therapists] on access to care, and total health outcomes.”<sup>3</sup> The U.S. Federal Trade Commission supported dental workforce expansion in November 2014, noting that expanding the supply of dental therapists is “likely to increase the output of basic dental services, enhance competition, reduce costs and expand access to dental care.”<sup>4</sup> The National Governors Association’s January 2014 issue brief on “The Role of Dental Hygienists in Providing Access to Oral Health Care” found that “innovative state programs are showing that increased use of dental hygienists can promote access to oral health care, particularly for underserved populations, including children” and that “such access can reduce the incidence of serious tooth decay and other dental disease in vulnerable populations.”<sup>5</sup> **There is no dispute that new types of dental providers are needed; the disagreement relates to what types of new providers are needed. This underscores the need for demonstration projects under Section 340G-1 exploring what types of new providers work best in various settings.** Frankly, it is

<sup>2</sup> <http://familiesusa.org/press-release/2015/families-usa-proposes-health-reform-20>

<sup>3</sup> (<http://ndaonline.org/position-on-access-to-care-and-emerging-workforce-models>)

<sup>4</sup> [https://www.ftc.gov/system/files/documents/advocacy\\_documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf](https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf)

<sup>5</sup> <http://www.nga.org/files/live/sites/NGA/files/pdf/2014/1401DentalHealthCare.pdf>

only ADA that actively works to block funding for Section 340G-1. ADA should be required to supply evidence justifying their persistent opposition to Section 340G-1. ADHA believes that a fact-based decision should be made by this Subcommittee with respect to Section 340G-1.

**Dentist Shortage and Dental Hygienist Surplus Calls for Better Utilization of Dental Hygienists**  
In February 2015, HRSA projected that all 50 states and the District of Columbia will experience

a shortage of dentists by 2025. In contrast, there will be an excess supply of dental hygienists at the national level while five states (MI, MT, ND, SD, and WV) will experience dental hygienist shortages from 21-93 FTEs.<sup>6</sup>

**Title VII Program Grants to Expand and Educate the Dental Workforce –  
*Fund at a level of \$35 million in FY 2016***

ADHA is pleased dental hygienists are recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the “General, Pediatric, and Public Health Dentistry” grants. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

**Oral Health Programming within the Centers for Disease Control (CDC) – *Fund at a level of \$20 million in FY 2016***

ADHA joins with others in the dental community in urging \$20 million for oral health programming within the CDC. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants will serve to facilitate improved oral health leadership at the state level; support the

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<sup>6</sup> HRSA March 2015 “National and State-Level Projections of Dentists and Dental Hygienists in the U.S., 2012-2025”  
<http://bhpr.hrsa.gov/healthworkforce/supplydemand/dentistry/nationalstatelevelprojectionsdentists.pdf>



collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services; enable states to be innovative and promote a data-driven approach to oral health programming.

**National Institute of Dental and Craniofacial Research – *Fund at a level of \$425M in FY 2016***

NIDCR cultivates oral health research that has led to a greater understanding of oral diseases

and their treatments and the link between oral health and overall health. Research breeds

innovation and efficiency, both of which are vital to improving access to oral health care

services and improved oral status of Americans in the future. ADHA joins with others in the oral

health community to support NIDCR funding at a level of \$425 million in FY 2016.

**Conclusion**

ADHA is the largest national organization representing the professional interests of the nation's

more than 185,000 licensed dental hygienists. Thirty-seven states enable patients to directly

access oral health services provided by dental hygienists in settings outside the private dental

office. Sixteen State Medicaid programs provide direct reimbursement to dental hygienists for

services provided to Medicaid-eligible individuals. **ADHA urges the Subcommittee to lift the**

**block on funding for Section 340G-1 of the PHSA, dental workforce demonstration grants, in**

**its FY 2016 HHS funding bill.** Lifting the block on funding for these dental workforce grants

would be an important signal to states and to health care stakeholders that exploring new ways

of bringing oral health services to the underserved is a meritorious expenditure of resources.

Without the appropriate supply, diversity and distribution of the oral health workforce, the

current oral health access crisis will only be exacerbated. ADHA recommends funding at a level

of \$2 million for FY 2016 to support these vital dental workforce demonstration projects.

Armando Nahum

President – Safe Care Campaign

April 18, 2015

Dear Sir or Madam:

I humbly nominate myself, Armando Nahum, to serve on the Presidential Advisory Council on Combating Antibiotic Resistant Bacteria. As for the desired member category, I will leave that up to the committee to ascertain where I might be the best fit.

I am the President of Safe Care Campaign, which was created in 2006 after three members of my family were infected with healthcare associated infections in three different states, in three different hospitals within 10 months' time.

At the end, our son Josh died of an antibiotic-resistant Gram-negative bacteria infection that he caught from his medical care. Before he died, his infection caused so much pressure on his brain that it pushed part of his brain into his spinal column, making him a permanent ventilator-dependent quadriplegic. Josh was 27. It was then that I resolved to begin my journey to become an expert on infections and antibiotic resistance from the patient and family perspective.

My full time work with the campaign (since 2006) as an infection prevention advocate, as well as contributions through projects we co-produced with the CDC, the Georgia Hospital

Association, my work of co-creating a comprehensive Hospital Engagement Network (HEN) Guide for the Partnership for Patients (PfP), serving as a member of the Georgia Healthcare Associated Infection Advisory Committee and the Georgia Antibiotic Stewardship Subcommittee under the Georgia Department of Public Health (DPH), demonstrates my immense enthusiasm and ability to robustly contribute to this council.

In addition, I have had the pleasure to have worked with the National Quality Forum (NQF) as well as the National Priorities Partnership.

I thank you for this potential opportunity to contribute to this important and much needed work on Combating Antibiotic Resistant Bacteria. I am encouraged that it will take all of us, each with our unique expertise to make a measurable and sustainable difference in preventing antibiotic resistance going forward.

Kindest Regards,

Armando Nahum

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My CV follows.

## Armando Nahum

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In 2006, our family became the faces the American health care system has come to associate with the problem of health care acquired infections after 3 members of my family became infected in 3 different hospitals in 3 different states in 10 months' time, culminating with the death of my son, Josh. He died from an antibiotic-resistant Gram-negative bacteria infection. He was 27.

Just weeks after Josh's death, my wife Victoria and I created Safe Care Campaign ([www.safecarecampaign.org](http://www.safecarecampaign.org)) to bring a sharper focus on infection prevention within the American health care environment.

Safe Care Campaign partners with health care systems, hospital administrations and frontline caregivers to remind, provoke, motivate and inspire all who work within the continuum of care of their most noble challenge and moral duty to prevent these infections that unnecessarily harm and kill patients in the U.S.

In 2007 the Safe Care Campaign, along with the CDC produced the premiere hand-hygiene safety video, "Hand Hygiene Saves Lives". They tell us it is the 3<sup>rd</sup> most downloaded video on the CDC website.

The same year we also invented (along with the CDC and The Joint Commission) a free patient safety education program now in use at thousands of hospitals across the U.S. and the world. This program allows patients and their families to instantly access important safety videos 24/7 **at the bedside** simply through the use of strategically placed posters, by scanning QR codes with their smartphones. It allows patients to access safety information right when they need it without any staff time requirements, training or cost.

In 2012, under President Obama's Affordable Care Act and the Partnership for Patients I co-created H2Pi (The Healthcare and patient Partnership Institute) along with Dr. Timothy McDonald and Martin J. Hatlie. This institute is a free offering to hospitals wanting to engage patients and their families as well as reach the stated goals of President Obama's Partnership for Patients.

I currently sit on the Georgia Healthcare Associated Infection Advisory Committee and the Georgia Antibiotic Stewardship Subcommittee under the Georgia Department of Public Health (DPH).

**Footnote:**

The work of Safe Care Campaign's has been featured on many national and local television and radio programs including as well as numerous articles in journals and publications:

- ☐ The Dr. Oz Show
- ☐ The Situation Room with Wolf Blitzer
- ☐ CNN's The Empowered Patient
- ☐ The CBS Evening News with Katie Couric
- ☐ The Wall Street Journal
- ☐ The Washington Post
- ☐ The New York Times
- ☐ Infection Control Today



**Testimony of Peter Wilderotter**  
**President and CEO, Christopher & Dana Reeve Foundation**  
**United States House of Representatives**  
**Subcommittee on Labor, Health and Human Services, Education and Related Agencies**  
**Committee on Appropriations**

**April 20, 2015**

On behalf of the Christopher & Dana Reeve Foundation, I am pleased to offer this written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. The Christopher & Dana Reeve Foundation requests a \$7,000,000 appropriation for the Christopher & Dana Reeve Paralysis Resource Center to support programs, resources and services focused on the promotion of independence and quality of life for the over 5 million Americans living with paralysis.

Founded in 1982, the Christopher & Dana Foundation is committed to funding innovative research and improving the quality of life for the 5 million people living with paralysis through the Christopher & Dana Reeve Foundation Paralysis Resource Center (PRC).

I would like to take this opportunity to specifically thank the Subcommittee for their continued investment in the PRC. The Paralysis Resource Center was created in 2002 through a cooperative agreement with the Centers for Disease Control and Prevention with the goal of promoting the health, well-being and independence of people living with paralysis, mobility impairment and spinal cord injury.

In the intervening 12 years, the Paralysis Resource Center has provided comprehensive information, resource and referral services through information specialists, a substantial Quality of Life Grants Program, Peer and Family Support Program and a Paralysis Resource Guide. The PRC provides services and information to over 500 thousand individuals annually. The PRC supports the Quality of Life Grants Program, which has provided over \$18.2 million in grants to non-profit organizations that provide services to individuals with paralysis. The PRC also supports the NeuroRecovery Network, which is a cooperative network of cutting-edge, specialized centers across the country to provide and develop standardized activity-based rehabilitation therapies to promote functional recovery and improve the health and quality of life for people living with paralysis.

When the Administration for Aging and the Office of Disability within HHS were merged in 2012 to create the Administration for Community Living (ACL), the Foundation recognized an

opportunity to secure a new federal ‘home’ for the PRC that would enable its programs to better serve the SCI community. The ACL’s mission, to “maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers,” aligns with the PRC’s efforts to champion the health and quality of life for those living with paralysis. While proud of all that we achieved at the CDC, we were thrilled when the PRC was transferred to the Administration for Community Living (ACL) in 2013.

In our time under the ACL, the PRC has served as an anchor for the mobility impairment community continuing to providing resources, tools, services and supports. Over the past year, the Foundation has worked with ACL to reduce barriers for the mobility-impaired and encourage independence and participation in their communities. We are grateful for the PRC’s progress and impact in our time under the ACL.

We appreciate the difficult funding decisions Congress faces. It is my hope, that in these challenging times we can continue to work with the Subcommittee to ensure continued investment in the programs and agencies that have the greatest impact for the paralysis community.

Thank you, Mr. Chairman and Members of the Subcommittee, for the opportunity to submit my testimony.

April 20, 2015

Susan C. Haas, Executive Director & C.E.O.

Nevada Rural Counties RSVP Program, Inc.

**FY 2016 Written Testimony for the Record**

Nevada Rural Counties RSVP Program, Inc. (Rural RSVP) is a part of the National Senior Corps funded through the Corporation for National and Community Service (CNCS). Rural RSVP is a 501 (c) (3) non-profit service organization with a track record of success covering 41 years of award winning programs for seniors in Nevada. CNCS has awarded Rural RSVP \$147,683 for FY2015.

Rural RSVP's mission is to help frail, homebound, and low-income seniors remain independent by providing high quality programs which allow them to stay in their own homes with dignity. Additionally, RSVP coordinates a volunteer network of seniors who use their skills and talents to provide support to community agencies and address community needs through service.

The needs of the growing senior population in rural Nevada counties continues to be a challenge as seniors are living longer but not necessarily healthier lives. There will always be more need than can be met; however, with support from critical funding from CNCS, (along with funding from State of Nevada, local government, private foundations, local businesses, special events, and private donations) Rural RSVP is able to assist thousands of frail, homebound, and low income seniors age 60 and older who desperately want to remain independent.



A critical challenge is that in rural Nevada seniors are spread out over an area of 100,000 square miles of rural communities where they are isolated and social services are limited or not available. Rural RSVP, in many cases, is the only resource seniors have to access the lifesaving goods, services, and social interaction that they need. Increasing numbers of seniors are unable to remain independent and in their own homes resulting in costly institutionalization. When seniors are isolated and lack access to lifesaving goods and services they become stranded at home and are at risk for costly and unnecessary institutionalization. This creates a heavy burden on already stretched federal, state, county, and local resources, as well as overwhelming the capacity of care facilities that do exist.

Rural RSVP Volunteers are highly trained and their service is critical to the survival of the frail homebound seniors who need access to medical care, assistance with shopping and socialization, along with many other basic needs that are essential for remaining independent and at home. Through collaboration with caregivers, volunteers, physicians and other agencies, a care-partnership is formed where the senior being cared for is at the center of the relationship. RSVP's collaboration efforts have been very successful as we strive to create relationships which deliver person-centered care and care partnerships. Seniors receive the emotional reassurance derived from human contact which is so necessary for the confined, homebound, frail, elderly persons. They know that they can count on a RSVP volunteer to relieve stress and fear of being stranded or prematurely moved to a nursing facility.

The research study "Aging in Place in America" commissioned by Clarity and the EAR Foundation that examines the attitudes and anxieties of the nation's elder population found that

seniors fear moving into a nursing home and losing their independence more than death. The isolated homebound elderly are also more vulnerable to elder abuse and depression which can easily lead to suicide. The Department of Health and Human Services, Office of Suicide Prevention, tells us that Nevada seniors over 60 have the highest suicide rate in the nation, which is over double the national average for the same age group.

“Little things mean a lot. I feel like I just won a prize and got out of jail! Being able to get out of the house and walk around the store is such a gift.” - 90 year-old homebound senior on an outing with an RSVP Home Companion volunteer.

“I care for my 91 year old mom who has Alzheimer’s. The RSVP Program has changed our ability to complete our simplest tasks. The RSVP drivers are kind, patient, understanding and totally professional. They treat Mom with tremendous respect and dignity.” – Bonnie H., caregiver and RSVP client.

“My mother recently passed away but I will always be grateful that she was able to live in her own home until the end. She was 97 years old. Thank you RSVP.”  
– Julia H., caregiver

Rural RSVP is dedicated to providing high quality independent living programs that help keep seniors independent and in their own homes with dignity. Rural RSVP provides its services to seniors at no charge; however, volunteers are not free. They are a very valuable resource that

comes at considerable cost. Still, this is a mere fraction of the costs of premature institutionalization.

RSVP Programs include: 1) Home Companion Program provides homebound seniors companionship and essential services; 2) Homemakers provide housekeeping services; 3) Respite Care provides 24/7 caregivers with regular breaks and companionship and safety for the loved-one at home; 4) Escorted Transportation volunteers provide critical care trips to medical appointments and to pick up prescriptions or groceries; 5) Care Law Program attorney provides pro bono legal services for low-income seniors; 6) Lifeline Program is an emergency telephone response system; 7) Resistance Exercise Program provides seniors with light weights training to improve their mobility, balance, cognitive ability, and methods to gain muscle strength; and 8) Senior Farmer's Market Nutrition Program provides free coupons for fresh fruits and vegetables to low-income seniors.

“Helping others gave my life purpose. I was completely lost until I found RSVP”

– RSVP Lyon County Volunteer Field Representative

RSVP volunteers also serve their communities through a variety of non-profit organizations and government agencies needing manpower to carry out their missions. More than one hundred thirty eight partnering agencies have entered into a Memorandum of Understanding with RSVP, and RSVP in turn assigns volunteers to serve these organizations and agencies, which include hospitals, fire departments, libraries, colleges, museums, food banks, and animal shelters,

allowing seniors to keep active, follow their passions, and remain contributing members of society.

In 2014, more than 1,260 RSVP volunteers provided 105,000 hours of service to 4,480 rural Nevada seniors and to RSVP's collaborating agencies.

CNCS Funds will support 940 Rural RSVP volunteers who will provide direct service assistance to more than 4,000 frail, homebound and low-income seniors which will help them to remain independent and in their own homes with dignity. Comparatively, based on the estimated cost of \$78,000 (AARP Long-Term Care Calculator, 2015) per person, per year, in Nevada to institutionalize just one indigent person, \$147,683 would cover the costs of institutionalization for two seniors.

Whenever possible, living independently is the best possible solution as it saves millions of taxpayer dollars spent on unnecessary institutionalized care.

Keeping seniors in their own homes is advantageous for many reasons. Not only is it the most fiscally prudent way to help them, it's the right thing to do. People living at home continue to contribute to the local economy which makes for a healthy, vibrant community. CNCS provides a service that honors the elderly who have given so much to our communities and to our nation.



**NAEVR**

National Alliance For  
Eye And Vision Research

*Serving as Friends of the National Eye Institute*

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**WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR (FY) 2016  
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)  
AND THE NATIONAL EYE INSTITUTE (NEI)  
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED  
AGENCIES SUBCOMMITTEE OF THE HOUSE COMMITTEE ON APPROPRIATIONS  
April 29, 2015**

**EXECUTIVE SUMMARY**

**NAEVR requests Fiscal Year (FY) 2016 NIH funding of at least \$32 billion, waiving it from sequester cuts and Budget Control Act caps and improving upon the President's FY2016 funding proposal of \$31 billion.** This builds upon FY2014 and 2015 actions by Congress to restore the \$1.7 billion in FY2013 sequester cuts by enabling at least a 5 percent increase in the NIH budget, reflecting both modest growth and an inflationary increase—crucial since NIH has lost 22 percent of purchasing power since FY2003, in terms of constant dollars.

**NAEVR requests National Eye Institute (NEI) funding at \$730 million, fully restoring the \$36 million in FY2013 sequester cuts and enabling modest growth and an inflationary increase—crucial since NEI has lost 25 percent of purchasing power since FY2003.** NEI's FY2015 operating budget is still \$25 million below FY2012—the equivalent of 60 grants. The President's FY2016 proposed NEI funding of \$695 million would still be \$7 million below pre-sequester funding.

**AMERICANS FEAR VISION LOSS, WHICH IS A  
GROWING PUBLIC HEALTH PROBLEM**

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as age-related macular

degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This will grow to more than 50 million Americans by year 2020, driven by the aging of the population—the “Silver Tsunami” of the 78 million baby boomers who will turn age 65 this decade and experience increased risk for eye disease; the disproportionate risk/incidence of eye disease in Hispanics and African Americans; and vision loss as a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to obesity.

In September 2014, NAEVR’s educational foundation, the Alliance for Eye and Vision Research (AEVR), released results of a new poll entitled *The Public’s Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease*, commissioned by Research!America and conducted by Zogby Analytics with a grant from Research to Prevent Blindness (RPB), a private vision funding foundation which conducted the first-ever poll of the public’s attitudes about vision loss in 1965. The 2014 poll—the most rigorous conducted to-date of attitudes about vision and vision loss among ethnic and racial groups including non-Hispanic Whites, African Americans, Hispanics, and Asian Americans—found, in part, that:

- a significant number of Americans across all racial lines rate losing their eyesight as having the greatest impact on their daily life, affecting independence, productivity, and quality of life.
- African Americans, when asked what disease or ailment is the worst that could happen, ranked blindness first, followed by HIV/AIDS. Hispanics and Asians ranked cancer first and blindness second, while non-Hispanic Whites ranked Alzheimer’s disease first, followed by blindness.

- America's minority populations are united in the view that vision research should be a national priority and that the current annual federal funding of \$2.10 per-person, per-year is not enough and should be increased.

In June 2014, Prevent Blindness (PB) released a report entitled *The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems*, commissioned from the University of Chicago's National Opinion Research Center (NORC). It estimates the current annual cost (direct and indirect costs) of vision disorders at \$145 billion, an increase of \$6 billion from the \$139 billion estimate in PB's 2013 study entitled *Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States*, which also concluded that direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's 2014 study projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to \$373.2 billion in 2050 when expressed in 2014 dollars—which is \$717 billion when adjusted for inflation. Of the \$373.2 billion estimated 2050 costs, \$154 billion or 41 percent will be borne by the federal government as the Baby-Boomers age into the Medicare program.

PB's 2014 report also concludes that the prevalence of vision disorders and costs will shift to conditions that are more common at older ages and for minorities:

- The age 90-plus population will see the highest rates of growth in prevalence and costs by 2050, since it will be the fastest growing segment of the U.S. population, reflecting the aging over the next 40 years of the Baby-Boom generation.

- The prevalence of eye diseases is going to increase by 60 to 80 percent by 2050 due to cataracts in the growing older population and diabetic retinopathy and glaucoma in growing African American and Hispanic populations.

### **NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION IMPAIRMENT GROWS**

In FY 2015, NEI's operating budget is still \$25 million below the FY2012 level due to a combination of the FY2013 sequester cut, lack of inflationary increases, and a reduction in NEI's appropriation due to the transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding to NEI was not committed indefinitely, its return to NIH Central in the amounts of \$5.6 million (FY2013), \$6.9 million (FY2014), and \$7.4 million (FY2015) has essentially cut NEI's budget further, resulting in a new baseline upon which any future funding increases are based. Even though the President's budget would increase NEI funding to \$695 million, its budget would still be \$7 million below the FY2012 pre-sequester level.

NEI's FY2015 operating net budget of \$676 million, as well as the President's FY2016 proposed NEI budget of \$695 million, are each less than 0.5 percent of the \$145 billion annual vision disorder cost burden. The U.S. is spending only \$2.10 per-person, per-year for vision research at the NEI, while the 2013 PB report estimates that the cost of treating low vision and blindness is at least \$6,690 per-person, per-year.

### **\$730 MILLION FY2016 FUNDING ENABLES NEI TO PURSUE ITS AUDACIOUS GOAL OF RESTORING VISION**

NEI has lost 25 percent of its purchasing power since FY2003, and the \$25 million that its budget is down from FY2012 equates to 60 grants it cannot fund—any one of



which could have held the promise to save sight and restore vision. Although these goals would have seemed unattainable just a few short years ago, the NEI is pursuing vision restoration through its *Audacious Goal Initiative (AGI)* which focuses on regenerating neurons and neural connections in the eye and visual system. In February 2014, NEI Director Dr. Paul Sieving stated the following about the AGI:

“The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10-15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases.”

The AGI builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries—such as imaging technologies that enable researchers to non-invasively view in real-time biological processes occurring in the retina at a cellular level—to develop new therapies for degenerative retinal disorders.

These are ambitious goals that require increased—not decreased—funding. Our nation’s investment in vision health is an investment in its overall health. NEI’s breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

**In summary, NAEVR requests FY2016 NIH funding of at least \$32 billion and NEI funding of \$730 million to maintain the momentum of research.**

**To: The Appropriations Subcommittee for Labor, Health and Human Services**

**From: AmeriCorps Alums**

Mary Bruce  
AmeriCorps Alums, Co-Executive Director  
AmeriCorps Member, 1999-2000

Ben Duda  
AmeriCorps Alums, Co-Executive Director  
AmeriCorps Member, 1999-2001, 2003

Ana Estrada  
National Advisory Council Chair  
AmeriCorps Member, 1999-2001

Andrew Davis  
National Advisory Council Vice-Chair  
AmeriCorps Member, 1999-2001

**Date: April 20, 2015**

**Subject: FY16 Budget for the Corporation for National and Community Service (CNCS)**

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We are writing in support of the Corporation for National and Community Service (CNCS), on behalf of the more than 800,000 Americans who have served in AmeriCorps since 1994. At AmeriCorps Alums, the only national network of alumni of all AmeriCorps programs, our mission is to support each alum in reaching his or her full potential as an engaged citizen and civic leader. As alums, we know that national service was an opportunity to serve our nation and to make an impact. We have seen the lasting impacts of national service in rural and urban America, in schools and health centers, and in disaster recovery. **Therefore, we support \$1.6 billion for the Corporation for National and Community Service, which would support up to 150,000 AmeriCorps members in FY16.**

We have also seen the lasting impact of national service on our own lives – and an overwhelming majority of alumni agree. In fact, nearly 9 in ten alumni (88%) believe their AmeriCorps service was among the most significant professional experiences of their lives.

(Source: 2014 Alumni survey)

For example, in our 2014 survey of 5,000 alums in all 50 states, one AmeriCorps alum wrote, “I was on a path of failing out of college without a lot of direction or motivation. It is not an understatement to say that deciding to serve with AmeriCorps was the biggest turning point in my life. Since then, I’ve graduated from college . . . and [am now] part of a powerful network of catalysts for social change.”

Service with AmeriCorps not only provided us an opportunity to address America’s toughest problems, it also set us on a path of service, for life. When we joined AmeriCorps, we pledged to make America “safer strong, and healthier ... our year of service and beyond.” Alums take that pledge seriously. We make our communities safer, stronger, and healthier as social sector professionals, nonprofit board members, and volunteers. Nearly all (90%) report a desire to continue volunteering (vs. just 27% of Americans who volunteer Source: [Civic Life in America](#)). Three in four (72%) alums say they want careers that impact the world around them. Through service, we were better equipped to do this. Two in three (64%) alums strongly agree they gained valuable workplace skills through service. The Segal Education Award, earned through AmeriCorps Service, helps alums defray the costs of higher education as they pursue these careers. All told, two in three (64%) alums continue careers in the nonprofit or government sector.

The investment in AmeriCorps is a critical and cost-effective way to address America’s toughest problems. The return on this investment is evident not just in safer, stronger, healthier

communities, but also in a vibrant alumni network that continues to “get things done for America.” **We urge you, and every member of Congress who believes in our citizens’ ability to create lasting change for our nation, to invest in CNCS.**

If there is any additional information we can provide, please don’t hesitate to contact us.

In service,

Mary Bruce



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AmeriCorps Alums, Co-Executive Director

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### **About AmeriCorps Alums**

AmeriCorps Alums builds a community of engaged citizens and civic leaders that get things done for America. An enterprise of Points of Light, AmeriCorps Alums is the only national network that connects the nearly 1 million alumni of all AmeriCorps programs who have served since 1994 (including an estimated 80,000 new alumni each year) to the people, ideas, and resources that support their commitment to a lifetime of service. Learn more at [www.AmeriCorpsAlums.org](http://www.AmeriCorpsAlums.org)



## ***National Association of RSVP Directors***

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**Betty M. Ruth**  
**President**  
**National Association of RSVP Directors, Inc.**

We appreciate the opportunity to submit testimony about the funding level proposed for the RSVP program. RSVP is a senior volunteer program administered by the Corporation for National and Community Service (CNCS). **The National Association of RSVP Directors (NARSVPD) seeks an FY 2016 funding level of \$63 million for RSVP.** This is \$15 million above the President's request and would restore funding for RSVP to the level it enjoyed in FY 2010 and would provide for an additional 75,000 volunteers. NARSVPD also proposes that this increase be allocated to strengthen existing RSVP programs.

RSVP provides opportunities for people 55 and over to make a difference in their communities through volunteer service. RSVP offers maximum flexibility and choice to its volunteers by matching the personal interests and skills of volunteers with opportunities to help solve community problems. It offers supplemental insurance while volunteers are serving, pre-service orientation, and on-the-job training from the agency or organization where volunteers are placed. **RSVP volunteers get no stipend but are eligible for reimbursement for meals and mileage, as long as program budgets allow for it.**

**RSVP is not means tested and recruits volunteers without regard to income. Most serve between 10 and 40 hours a week, but there is no set schedule. RSVP is flexible and volunteers can be recruited and deployed to meet a wide variety of community challenges.**

**RSVP is cost-effective. The average federal RSVP grant is about \$75,000 – equal to the national annual median rate of the cost of a semi-private room in a nursing home rate of \$75,555 -- and the average annual cost per volunteer is \$202 Independent Sector values an hour of volunteer service at \$22. Using this multiple, RSVP volunteers provide about \$900 million worth of service to the nation each year.** Further, RSVP grantees must provide a match. The required non-federal share is a minimum 10 percent of the total grant in year one, 20 percent in year two, and 30 percent in year three and all subsequent years. Grants are awarded for a period of up to three years.

**RSVP volunteers improve the lives of their neighbors and friends every day by meeting the needs of their communities.** They help them prepare their tax returns, provide needed transportation services, offer respite to caregivers, deliver health and nutrition services, support veterans and military families, volunteer in parks, participate in disaster prevention and relief activities, and many other activities.

RSVP efficiently deploys 232,000 volunteers in more 625 programs that support the efforts of 38,000 community organizations across the nation. In FY 2014, RSVP volunteers delivered an estimated 40.4 million hours of service in their communities. Working through such networks as Area Agencies on Aging, city and county governments, local United Way organizations, social service agencies, faith-based organizations, and many others, RSVP volunteers served 329,000 veterans in activities such as transportation and employment service referrals; mentored more than 78,000 children; provided independent living services to 797,000 adults, primarily frail seniors; provided respite services to nearly 20,300 family or informal caregivers; engaged 20,100 veterans who served as RSVP volunteers and leveraged an additional 18,500 volunteers to support RSVP activities such as delivering meals to those in need and tutoring at-risk children.

**RSVP is an important source of disaster prevention and relief.**

For example:

- In the year following the 2013 tornado, more than 90 volunteers from RSVP of Central Oklahoma contributed 4,515 hours to nine nonprofit and state organizations working in the recovery effort. RSVP volunteers answered disaster hotlines, performed follow-up calls to families affected by the disaster, served food and provided companionship at day shelters, provided survivors with rides to medical appointments, and collected and distributed donated goods to disaster survivors. Shell Company of the Americas contributed \$50,000 to support the vital disaster recovery and preparedness services being provided by the RSVP of Central Oklahoma.

**RSVP helps maintain the social safety net.**

- The RSVP Program at the All Peoples Christian Center in Los Angeles mobilizes 375 volunteers. They manage and implement supplemental food distribution programs at four faith-based food distribution programs in South and Southeast Los Angeles. According to CNCS, “RSVP volunteers manage the full operations at each site .... This year more than 1100 low-income individuals and families received USDA food as well as fresh fruits and vegetables on a weekly basis. Some 60 percent of the recipients reported that these programs improved their diet and allowed them to pay for basic necessities like rent and utilities by cutting their grocery bills.” RSVP volunteers also conduct Spanish-English classes and mentor children.

**RSVP helps seniors to live independently in two ways: volunteering helps keep seniors vibrant and RSVP volunteers help meet the needs of seniors to keep them in their homes.**

- Twenty-five RSVP Volunteers in rural Pike County, Alabama transport other seniors, an average of 15 per week, to medical appointments, drug stores, and to buy groceries or other necessities on a daily and weekly basis. They provide over 2500 trips annually allowing these 86 seniors to get medical care and continue to live independently in their own homes. Another 25 RSVP Volunteers call 85 frail homebound seniors, mostly living in a rural area, on a daily basis providing outreach and interaction, helping them remain mentally alert, feel safer, and enabling them to remain in their homes longer and avoid early institutionalization. 15 RSVP volunteers assist daily and weekly with local meal deliveries to an average of 89 frail and homebound seniors. Last year over 4800 meals were delivered by RSVP volunteers to assist seniors in receiving a nutritious meal, interact with volunteers and enabling them to remain in their homes longer and avoid premature institutionalization. The average cost of nursing home care in Alabama is \$180.00 per day. That is \$65,700.00 per year, per person. With RSVP volunteer assistance, 86 seniors remain in their homes yearly and save over \$5,650,200.00 in nursing home costs to Alabama.

**RSVP volunteers support veterans and military families.**

- Pike County RSVP has 20 RSVP volunteers who serve with its Veterans and Military Families initiative in which Troy University provides a classroom with 60 available computers and RSVP volunteers assist with job search, applying online and mock job interviews for Veterans and military families, assisting veterans and military families in researching and locating housing, schools, and support services. All told,



these RSVP volunteers helped more than 200 veterans and military last year.

The National Association of RSVP Directors (NARSVPD) seeks an FY 2016 funding level of \$63 million for RSVP. This is \$15 million above the President's request and would restore funding for RSVP to the level it enjoyed in FY 2010 and would provide for an additional 75,000 volunteers. NARSVPD also proposes that this increase be allocated to strengthen existing RSVP programs.

Finally, **RSVP is a “destination” for retiring “baby boomers.”** 10,000 Baby Boomers are retiring everyday and will do so every day for the next 20 years RSVP is the only national program able to place large numbers senior volunteers in high quality volunteer positions. CNCS reported that RSVP has increased the number of baby boomers in the program and provides those volunteers with high quality activities that make use of their skills. Baby boomers in RSVP volunteer over 100 hours more than their counterparts who are not associated with RSVP. Virtually all of RSVP baby boomers who recruit/coordinate other volunteers are likely to continue in the program.

For additional information, contact: Betty Ruth, President, NARSVPD, at [bruth@al-rsvp.com](mailto:bruth@al-rsvp.com) or Gene Sofer, Washington Representative, at [eugenesofer@gmail.com](mailto:eugenesofer@gmail.com).

Testimony of Research!America to the House Committee on Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies

Submitted for the Record April 21, 2015

Contact: Caitlin M. Leach, Director of Policy and Advocacy, cleach@researchamerica.org

Research!America, a public education and advocacy alliance committed to speeding the pace of medical progress and strengthening our nation's scientific enterprise, appreciates your stewardship over such a critical subset of our nation's discretionary funding priorities. As the subcommittee begins the process of prioritizing FY16 funding, we urge you to consider the following thoughts on three federal agencies within your purview: the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ).

#### **NIH as a driver of innovation**

In FY16, we urge you to provide at least \$33.3 billion in NIH funding to drive us beyond the stagnation that squanders opportunities to advance science and strengthen our nation. Research funded by the NIH at universities, academic medical centers, independent research institutions and small businesses across the country lays the foundation for new product development by the private sector. Since the research NIH supports is at the non-commercial stages of the research pipeline, NIH funding does not compete with, but rather lays the foundation for, critical private sector investment and development.

The secrets of diabetes, Alzheimer's, Parkinson's, myriad cancers and many other diseases can and will be unlocked by science. The question is not if, but when... unless we dismiss the significance of such progress and continue to allow research resources to stagnate. And our

nation's best weapon against spiraling health care costs is research. Ignoring growing health care costs is a ticket to disaster. Alzheimer's disease alone is projected to cost the federal government over \$1 trillion during the next 20 years. Ultimately, we must prevent and cure disease in order to tackle the costs associated with it.

Our request for FY16 represents a 10% increase over current NIH funding levels. While this is clearly an ambitious target, we believe that NIH-funded research is of sufficient national benefit to warrant a significant infusion of new funding. The percentage of grants NIH approves for funding is at historic lows, not because of an increase in submissions or a decline in impactful research ideas, but because inflation has severely eroded NIH's purchasing power. A 10 percent funding increase won't restore grant approval rates to historic levels, but it would meaningfully increase the volume of important medical research. Given the positive impact of research, not only on human health, but on our country's economic and - as global health threats reach our shores - national security interests, meeting the challenge of securing a 10% increase for NIH is a strategically sound objective.

### **CDC as a first responder**

In FY16, we urge you to provide at least \$7.8 billion in CDC funding to bolster the agency's ability to protect the public health. The CDC engages in research and operational strategies that stem deadly and costly pandemics, bolster our nation's defenses against bioterrorism, and help prevent the onset of debilitating and expensive diseases. The CDC is the nation's first responder when lethal viruses and infections, including life-threatening, costly drug-resistant infections and deadly global threats like Ebola, arise. In addition, CDC is also charged with investigating

cancer clusters and other serious community health threats. The CDC also facilitates disease registries, which provide crucial insight into disease burden and are destined to play an increasingly important role as data analytics transform 21st century research.

The CDC received welcome supplemental funding to help combat Ebola, but public health is an ongoing pursuit and Ebola was a wake-up call that calls for a greater commitment to public health research, practice, and preparedness on a sustained basis. It is more efficient and cost effective to be in front of an outbreak or biological attack than to take reactionary measures, and Americans' best interests are served when disease and disability are not just treatable, but preventable. These objectives are central to the CDC's mission and we ask that the Subcommittee to provide the CDC with the resources it needs to meet that mission, day in and day out.

**AHRQ translates medical innovation into the right care at the right time, saving lives and dollars**

We are truly grateful that in FY15, appropriators granted AHRQ long overdue budget authority. AHRQ plays a unique and critical role in the delivery phase of medical innovation, and Americans deserve a concrete federal commitment to the patient-focused, lifesaving research it funds. For FY16, we urge you to provide at least \$375 million in funding for AHRQ and to preserve its budget authority.

Among its many contributions to the health and well-being of Americans, AHRQ-supported research combats medical errors and improves the quality of care to help reduce the length and

intensity of disability and disease. Other research funded by AHRQ helps ensure new treatment options reach patients on a timely basis, and helps patients and physicians make informed treatment decisions that improve outcomes and reduce costly “false starts” in the provision of health care services. Research supported by AHRQ also identifies inefficiencies in health care delivery that inflate the cost of public and private insurance.

Just one of many success stories is AHRQ’s issuance of new standards of care and practices related to central line-associated bloodstream infections. The implementation of the guidelines resulted in a reduction of up to two-thirds of cases during early rollout studies. With an annual estimated 80,000 cases, up to 28,000 deaths and an average cost per patient of \$45,000, this has the potential to save \$2.3 billion annually in health care costs. Given the enormity of the challenge of inefficiency in health care delivery, AHRQ is severely underpowered.

Research!America appreciates the difficult task facing the subcommittee as it seeks to simultaneously confront the budget deficit, strengthen the U.S. and promote the well-being of Americans, and we recognize that our funding requests are ambitious. However, funding for NIH, CDC and AHRQ is a unique opportunity to advance all three objectives. In fact, there are few federal investments that confer as many benefits as funding for NIH, CDC and AHRQ - new cures, new businesses, new jobs; innovative solutions that improve healthcare delivery and optimize the use of limited health dollars; and a public health system nimble and sophisticated enough to meet the myriad, predictable and unpredictable challenges that *will* emerge over time.

We believe that allocating \$33.3 billion to the NIH, \$7.8 billion to the CDC, and \$375 million to AHRQ is a pragmatic strategy for securing a safer and healthier future for our country, and we thank you for considering these funding requests.

**Testimony submitted on behalf of the American Physiological Society****David M. Pollock, Ph.D., President**

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). Research carried out by the NIH contributes to our understanding of health and disease, which allows all Americans to look forward to a healthier future. The APS urges you to make every effort to provide the NIH with at least \$32 billion in FY 2016. This is necessary to prevent further erosion of research capacity.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. The federal government is the primary funding source for discovery research through competitive grants awarded by the NIH. Although the private sector partners with academic researchers to develop research findings into new treatments, industry relies upon federally funded research to identify where innovation opportunities can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. However, this position of leadership is at risk as other nations, including China, increase their investments in research and development while the United States investment has lagged in recent years.

Federal research dollars also have a significant impact at the local level: more than 80% of the NIH budget is awarded throughout the country to researchers who use grant funds to pay

research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

### **Challenges facing the scientific community**

Twenty years ago leaders in Congress undertook the grand challenge of doubling the budget of the NIH with a vision of moving biomedical science forward and improving quality of life for people around the world. The investment that Americans made between 1995 and 2003 allowed the biomedical research enterprise to grow in many ways: more research was funded, new investigators were trained, and the infrastructure required to support the science expanded to fit the need.

Unfortunately, the NIH budget has declined in constant dollars each year since 2004, causing a slow erosion of research capacity. Between FY 2003 and 2015, NIH's capacity to support research declined by 22.9%. This was further exacerbated by the spending caps put in place by the Budget Act of 2011, which caused significant cuts for the agency in FY 2013. One analysis showed that NIH supported approximately 1000 fewer investigators in FY 2013 as a result of budget cuts.<sup>1</sup> Researchers who lose their funding face an uncertain future as there are few options to sustain their research without federal grants. Losing federal support puts at risk the investment that it took to build those programs over many years. It also means that talented individuals working in those labs will have to look elsewhere for increasingly scarce jobs. As a result of stagnant funding for NIH, scientists at all stages of their careers struggle to maintain their research programs.



Fundamental changes are needed to ensure long-term sustainability for the scientific enterprise and many groups have undertaken efforts to maximize the amount of research that can be carried out with the resources available. However, the reality is that scientists are approaching the point where they can no longer “do more with less” and as a result, less research will be accomplished. We urge Congress to make every effort to provide NIH with the resources necessary to sustain the scientific enterprise and move research forward. The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with at least \$32 billion in FY 2016.

### **The promise of research**

This year the NIH has announced plans to advance scientific priorities including:

- Continued investment in the **Brain Research through Advancing Innovative Neurotechnologies** (“BRAIN”) initiative. The BRAIN initiative brings together researchers from diverse disciplines to tackle major gaps in current knowledge about the brain and brain diseases.
- A new **Precision Medicine** initiative would invest heavily in cancer genomics, and develop a national research cohort of 1 million participants.
- Resources would also be devoted to a multi-agency **Antimicrobial Resistance** initiative to address the growing public health crisis represented by the rise of multiple drug resistant pathogenic bacteria.

These important projects require significant resources, and at a time of constrained budgets, that will further diminish funding for investigator-initiated grants that focus on major disease areas

including cancer and cardiovascular disease, the major killers of American citizens. The NIH system of allowing investigators to develop and propose ideas, which are then evaluated by their peers and selected for funding based on their merit has fostered a research enterprise that is second to none and has been the source of most every major new discovery in medicine. Increasing the NIH budget to \$32 billion would provide funding for priority projects as described above, while also providing resources for individual scientists to pursue creative new avenues of research.

The NIH also uses the Institutional Development Award (IDeA) Program to broaden the geographic distribution of NIH funds by providing support to researchers and institutions in areas that have not previously received significant NIH funding. IDeA builds research capacity and improves competitiveness in those states by developing shared resources, infrastructure and expertise. Networks established through this program expand research opportunities for students and faculty at predominantly undergraduate institutions and enhance the level of science and technology knowledge of the workforce in IDeA states. The program currently serves institutions and researchers in 23 states and Puerto Rico. The APS believes this program is an important way to broaden participation in the scientific workforce.

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

<sup>1</sup> <http://www.asbmb.org/asbmبتoday/201403/PresidentsMessage/>



**Testimony of Dr. Ford W. Bell,  
President of the American Alliance of Museums,  
[www.aam-us.org](http://www.aam-us.org)  
to the House Appropriations Subcommittee  
on Labor, Health and Human Services, Education and Related Agencies  
in support of the IMLS Office of Museum Services  
April 23, 2015**

Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee, thank you for allowing me to submit this testimony on behalf of our members and the nation's larger museum community. My name is Ford Bell and I serve as President of the American Alliance of Museums. I respectfully request that the Subcommittee make a renewed investment in museums in Fiscal Year (FY) 2016. I urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its authorized level of \$38.6 million.

The Alliance is proud to represent the full range of our nation's museums—including aquariums, art museums, botanic gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others—along with the professional staff and volunteers who work for and with museums.

Museums are economic engines and job creators: We are proud to report that U.S. museums employ 400,000 people and directly contribute \$21 billion to their local economies.

This Subcommittee may be especially interested in the ways museums are providing educational programming and the results of this investment:

- Museums spend more than \$2 billion each year on education activities; the typical museum devotes three-quarters of its education budget to K-12 students, and museums receive approximately 55 million visits each year from students in school groups.
- Children who visited a museum during kindergarten had higher achievement scores in reading, mathematics and science in third grade than children who did not. This benefit is also seen in the subgroup of children who are most at risk for deficits and delays in achievement.
- According to a recent study by researchers at the University of Arkansas, students who attended a field trip to an art museum experienced an increase in critical thinking skills, historical empathy and tolerance. For students from rural or high-poverty regions, the increase was even more significant.
- Museums help teach the state, local or core curriculum, tailoring their programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography and social studies.
- Many museums are tailoring programs to serve homeschooling families.

IMLS is the primary federal agency that supports the museum field, and OMS awards grants in every state to help museums digitize, enhance and preserve their collections; provide teacher training; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public.

In late 2010, legislation to reauthorize IMLS for five years was enacted (by voice vote in the House and by unanimous consent in the Senate). The bipartisan reauthorization included several

provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response and statewide capacity building. The reauthorization also specifically supports efforts at the state level to leverage museum resources, including statewide needs assessments and the development of state plans to improve and maximize museum services throughout the state. That bill (Public Law 111-340) authorized \$38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The Fiscal Year 2015 appropriation of \$30.1 million represents a nearly 15% decrease from the FY 2010 appropriation of \$35.2 million.

We applaud the Administration's Fiscal Year 2016 budget for requesting a significant increase—to \$35.1 million—for the Office of Museum Services. It would help museums make an impact in several priority areas identified by the agency, such as STEM education and makerspaces, a comprehensive collections care survey, and early learning. We also applaud the 132 Representatives who wrote to you in support of FY 2016 OMS funding, including subcommittee members Fattah and Lee.

Here are a few examples, just from 2014, of how IMLS Office of Museum Services funding is used:

**Traveling Natural History Science and STEM Curriculum—Sam Noble Oklahoma Museum of Natural History (Norman, OK)** was awarded \$123,132 to develop traveling natural history science curricula kits for K-12 students. This project will expand the museum's outreach program, featuring STEM (Science, Technology, Engineering, and Mathematics)

content with a focus on Oklahoma geology, life, and cultural science. The museum will share the educational kits, featuring materials aligning with state educational standards, with teachers across Oklahoma. The museum's digitization of the kits will increase the capacity and number of teachers who have access to the material and enable students to experience high-quality STEM educational opportunities offsite and online.

**Classroom Learning Experiences—Art Museum of Eastern Idaho (Idaho Falls, ID)**

was awarded \$18,440 to expand its "ARTworks" education program by sending museum-sanctioned artist instructors into 100 public school 3rd and 4th grade classrooms in eastern Idaho to teach grade-relevant lessons aligned with the Idaho Humanities Achievement Standards. The ARTworks program will play an important role in strengthening critical thinking, problem solving, creativity, and self-direction among students.

**Increasing Access to Collections—Peabody Museum of Natural History (Yale University, New Haven, CT)**

was awarded \$136,615 to rehouse three components of its invertebrate zoology collection. Much of this material is associated with the research of Yale's first professor of zoology, Addison E. Verrill, and it includes previously unrecognized type specimens. As a result of this grant, the collection will be catalogued and preserved in a state-of-the-art storage facility with greater accessibility for researchers and the public.

**School Partnerships and Outreach—California African American Museum (Los Angeles, CA)**

was awarded \$131,835 to redesign its hands-on learning exhibition, the Gallery of Discovery, publish a curriculum aligned with California state standards, and provide on-site professional development

workshops and in-class support to a network of teachers from local schools. Through CAAM's Education Expanded! Initiative, the grant will help the museum address the disparity of access to arts and cultural opportunities among middle and high school students from Title I schools.

It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the dollar-for-dollar match required of museums, grants often spur additional giving by private foundations and individual donors. Two-thirds of IMLS grantees report that their Museums for America grant positioned the museum to receive additional private funding.

IMLS grants to museums are highly competitive and decided through a rigorous, peer-review process. Even the most ardent deficit hawks view the IMLS grant-making process as a model for the nation. Due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year. In 2014:

- Only 35% of Museums for America/Conservation Project Support project proposals were funded;
- Only 22% of National Leadership project proposals were funded;
- Only 17% of Sparks Ignition Grants for Museums project proposals were funded;
- Only 64% of Native American/Hawaiian Museum Services project proposals were funded; and
- Only 37% of African American History and Culture project proposals were funded.

If I can provide any additional information about the essential role of the museums in your community, I would be delighted to do so. Thank you once again for the opportunity to submit this testimony today.



# TESTIMONY ON THE FY 2016 BUDGET BY

LAWRENCE MEHREN, CHIEF EXECUTIVE OFFICER, ACCELERATE DIAGNOSTICS, INC.

TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES, APRIL 22, 2015

Chairman Cole, Representative DeLauro and members of the Subcommittee, thank you for the opportunity to submit testimony on the Fiscal Year 2016 budget. I am Lawrence Mehren, Chief Executive Officer of Accelerate Diagnostics, Inc., of Tucson, Arizona, an *in vitro* diagnostics company dedicated to providing solutions to the global challenge of antibiotic resistant organisms. In view of the growing public health crisis related to untreatable bacterial infections, we urge Congress to provide funds to implement the National Strategy to Combat Antibiotic Resistant Bacteria and support the Centers for Disease Control's Antibiotic Resistance Solutions Initiative. We support the following HHS budget requests:

Centers for Disease Control and Prevention (CDC): Antibiotic Resistance Solutions Initiative (\$264 million); National Healthcare Safety Network (NHSN) (\$32 million); Advanced Molecular Detection (AMD) Initiative (\$30 million)

National Institutes of Health (NIH): National Institute of Allergy and Infectious Diseases (NIAID) (\$4.615 billion with an increase of \$100 million to spur rapid diagnostics R&D)

HHS Assistant Secretary for Preparedness and Response (ASPR): Biomedical Advanced Research and Development Authority (BARDA) (\$522 million)



Each year in the United States at least two million people are infected with bacteria that are resistant to antibiotics; some 23,000 die as a direct result of these infections. This represents an immediate and growing crisis that threatens public health and national security, warranting increased federal funding to deal with antibiotic resistance (AR).

In particular, there is a critical need for improved AR diagnostic technologies, including rapid identification (ID) of pathogens, and high speed antibiotic susceptibility testing (AST). These are key to effective patient treatment, stewardship of life-saving antibiotic drugs, and reduced healthcare costs. Additionally, Congress should encourage adoption and utilization of new diagnostic technologies, with education of physicians and pharmacists, as well as appropriate reimbursement.

Hospitalized patients with bacterial infections typically endure 2-3 day delays before current microbiology laboratory methods reveal the specific pathogen and optimal antibiotic therapy. Before that, broad spectrum, empiric antibiotics are typically administered in the hope that they will be effective against the infection in the particular patient.

The result: delayed optimal treatment, greater patient distress, poorer outcomes, higher treatment costs and dilution of antibiotic effectiveness (as microbes adapt to them). All of these are obviously unacceptable.

Accelerate Diagnostics is developing an ID/AST system that identifies pathogens within one hour, and, using computer-controlled microscopy and image analysis

software, pinpoints the effective antibiotic within five hours from the availability of the sample.

The Accelerate ID/AST system includes four key technologies:

- Automated sample preparation
- Fluorescence In Situ Hybridization for quantitative and definitive bacterial identification
- Automated, time-lapse microscopy of immobilize bacterial cells challenged with antibiotics for susceptibility testing
- High-powered image analysis of bacterial growth and associated algorithms for Minimum Inhibitory Concentration (MIC) and antibiotic susceptibility determination

Accelerate plans to support the medical community with rapid diagnostic information for a broad range of infection types including bloodstream infections (septicemia), pneumonia, skin and wound infections as well as urinary tract infections.

Our company is entering into preclinical studies with our ID/AST platform in preparation for its registration trial for positive blood culture specimens. Accelerate recently entered into a research collaboration with the Rapid Antimicrobial Susceptibility Testing Laboratory at the CDC to develop tests for the rapid analysis of antibiotic-resistant biothreat agents based on this same platform. In a project funded by NIH, the Denver Health Medical Center will use the Accelerate ID/AST System to develop

a test to detect CRE directly from blood, with corresponding antibiotic susceptibility, in less than three hours.

Following are summaries of the budget items we support:

#### Centers for Disease Control and Prevention (CDC)

- Antibiotic Resistance Solutions Initiative (\$264 million), for prevention programs in all 50 states and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics; and for a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria
- National Healthcare Safety Network (NHSN) (\$32 million), for expansion of the Network to more than 17,000 facilities, providing real-time data about antibiotic use and trends, targeting health care facilities that need additional assistance using NHSN data, and implementing prevention strategies
- Advanced Molecular Detection (AMD) Initiative (\$30 million), allowing CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population, to effectively guide public health action

#### National Institutes of Health (NIH)

- National Institute of Allergy and Infectious Diseases (NIAID) (\$4.615 billion), including an increase of \$100 million to spur R&D for new rapid diagnostics to help ensure that antibiotics are prescribed appropriately, develop a national database of genome

sequence data of all reported human infections with antimicrobial-resistant microorganisms, launch a large-scale effort to better understand drug resistance, and create a rapid-response clinical trial network to test new antibiotics on individuals infected with highly resistant strains

HHS Assistant Secretary for Preparedness and Response (ASPR)

- Biomedical Advanced Research and Development Authority (BARDA) (\$522 million), including \$192 million dedicated to antimicrobial R&D, utilizing public-private partnerships to address the market failure in antibiotic R&D

Investing in AR will have a profound effect. CDC Director Tom Frieden projects that with proper funding, over five years the CDC can prevent at least 600,000 multi-drug-resistant infections, prevent at least 37,000 deaths from multi-drug resistant organisms and avert nearly \$8 billion in healthcare costs.

We would be delighted to meet with members of the committee or staff to provide further details and respond to your questions. Thank you for your consideration.



Lawrence Mehren  
Chief Executive Officer

**Statement of Patricia de Stacy Harrison  
President and CEO, Corporation for Public Broadcasting  
Before the Subcommittee on Labor, Health and Human Services, Education and Related  
Agencies, House Committee on Appropriations  
April 22, 2015**

Chairman Cole, Ranking Member DeLauro and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests level funding of \$445 million for Fiscal Year 2018, \$40 million in FY 2016 for the first year of a \$197 million multi-year request to replace the current public television interconnection system, and \$25.74 million for the Department of Education's Ready To Learn program.

Forty-seven years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise to the American people-- that we would provide high quality trusted content that educates, inspires, informs and entertains. We ensure a safe place where children can learn; high-quality educational content for teachers in the classroom and children schooled at home; reliable and trusted news and information; and emergency alert services. Through our commitment to lifelong learning public media is providing an education continuum from the youngest to oldest Americans.

Through the 1,400 locally owned and operated public radio and television stations throughout American, we support more than 20,000 local jobs in rural and urban communities. Over 70 percent of CPB's appropriation goes directly to local stations who work in partnership with their communities to best serve local interests and concerns. Public media reaches nearly 99 percent of the American population—with an overwhelming majority of them consuming public media throughout the year.

The federal appropriation is the essential investment that ensures your constituents will have access to public media for free and commercial free. President Ronald Reagan said, “government should provide the spark and the private sector should do the rest.” America’s local public media stations utilize the “spark,” which amounts to about \$1.35 per American and comprises approximately 10 to 15 percent of a stations’ budget, and raise the rest from their viewers, listeners, donors and contributors. The result is a uniquely entrepreneurial system with a track record of value delivered to all citizens.

Our trusted, noncommercial services available for free to all Americans is especially important to those living in rural communities where the local public media station is sometimes the only source of broadcast news, information and educational programming. For these smaller stations serving rural, minority and other underserved communities, the federal dollars provide much more than just a spark, in some cases CPB’s investment can represent as much as 40 percent of their budget.

Public media’s contribution to education—from early childhood through adult learning—is well documented. We are America’s largest classroom, with proven educational content available to all children, including those who cannot afford preschool. Further, our content is repeatedly regarded as “most trusted” by parents, caregivers and teachers. CPB’s work with the Department of Education’s Ready To Learn program is an excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities. Twenty years ago, Congress recognized the reach and potential of public media to help disadvantaged children become better prepared to enter school. Since that time, and as technology has evolved, public media has provided coordinated and connected learning experiences for children across multiple platforms, including TV, Internet, mobile, and in

multiple settings, such as classrooms, summer and after-school programs, and at home. More than 80 studies have proven that this program's content builds and improves early literacy skills for high-need children ages two to eight.

Public media is also differentiated from commercial media through content that matters and engagement that counts. An example of this is CPB's "American Graduate" initiative, which tells the story behind the statistic of one million young people failing to graduate from high school every year. Our stations told the stories and communities throughout the country responded. Over the past four years more than 80 public media stations located in at-risk communities in 33 states have worked with more than 1,400 national and community-based partners to bring together diverse stakeholders and community organizations all working toward a national graduation rate of 90 percent by 2020. We are pleased to report that as a result of our and others combined efforts, in 2014, the high school graduation rate rose to 85 percent for the first time in our nation's history.

Public media is utilizing today's technology to provide content of value to millions of citizens. CPB strategically focuses investments through the lens of what we refer to as the "Three D's" —Digital, Diversity and Dialogue. This refers to support for innovation over multiple platforms, including digital; content that is for, by and about Americans of all backgrounds; and services that foster dialogue between the American people and the public service media organizations that serve them. Our Act ensures diversity in programming by requiring CPB to fund independent and minority producers. CPB fulfills this obligation, in part, by funding the Independent Television Service, the five Minority Consortia entities in television, several public radio consortia and numerous minority public radio stations. In addition, CPB,

through its Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

Further, as newspapers across the country have scaled back their operations, public media has stepped into the void. Local stations have been working to fill the gap by building creative ventures and partnerships to provide their communities with much-needed local, regional, and statewide news. CPB has helped these endeavors by funding 11 journalism collaborations.

The work of public media goes beyond broadcast. Public television and radio stations are increasingly effective partners with state and local public safety, law enforcement and first responder organizations—connecting these agencies with one another, with the public, and with vital data-casting capabilities in times of crisis. CPB is also supporting stations, both financially and by defining best practices, so that they may create more public-private partnerships locally and regionally, bringing more services and benefits to their communities. For example, CPB's Veterans Coming Home project builds on public media's strengths to address the needs of veterans in local communities. Stations and their partners are communicating veterans' stories through award winning reporting, documentaries and online content; convening local events such as job fairs and town hall meetings that connect veterans with resources; and collaborating with local organizations to identify local services available to veterans.

Last, as we near the expiration of our current Interconnection System satellite leases in September 2016 we must look ahead to the system that will serve public television stations for the next decade. Congress recognized the need for an interconnection system in 1967 when it passed the Public Broadcasting Act; it has maintained that commitment ever since with the funding of five generations of interconnection systems. Since 1988, Congress has supported a separate appropriation for public media's interconnection needs.



Interconnection is the backbone of public broadcasting. Without it, there is no nationwide public media service. It is used by PBS and many other public television entities to distribute television content and related materials to non-commercial, educational television licensees across the entire country. Additionally, interconnection also serves as the failsafe mechanism for Presidential emergency alerts. Transmitting across 367 stations in all states and territories, PBS' Warning Alert and Response Network provides redundancy which enables wireless carriers to bypass network congestion caused by emergencies. The next interconnection system will employ two-way capability, paving the way for enhanced collaboration during times of emergency.

Public media's treasure trove of content and services, available to all Americans for about \$1.35 per American per year, allows public media stations to training teachers and help educate America's children. We are providing journalism beyond just a sound-bite that truly provides citizens with the information they need to make informed decisions about local issues; to have in depth knowledge through fact based reporting about national and global news. We make the arts accessible to all Americans; and provide emergency alert services for communities. CPB ensures that 95 cents of every dollar received goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead. Congress' support of our request will allow stations to continue providing high quality trusted content and materials that educate and strengthen our civil-society.

Mr. Chairman this is only part of the story of America's public media system. Public media is truly a national treasure. I thank you for allowing me to submit this testimony and appreciate your consideration of our request for funding.

**TESTIMONY SUBMITTED  
to the**

**HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE  
ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

**by  
Susan L. Vaughn, Director of Public Policy  
for the  
National Association of State Head Injury Administrators**

**DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES CENTERS  
HEALTH RESOURCES AND SERVICES ADMINISTRATION AND  
ADMINISTRATION FOR COMMUNITY LIVING**

April 22, 2015

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2016 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the Department of Health and Human Services (HHS). We are pleased that Congress passed the TBI Reauthorization Act of 2014 which includes funding authority to expand capacity within States for rehabilitation and community services and supports for individuals with TBI and their families. In keeping with the legislation, which removed Health Resources and Services Administration (HRSA) from the sections authorizing appropriations for both the State Grant and the Protection and Advocacy (P&A) Grant programs, NASHIA **recommends transferring the HRSA TBI State Grant and P&A Grant Program to the Administration for Community Living (ACL) to maximize resources necessary to support the array of services and supports needed following a brain injury across the lifespan and to:**

1. integrate TBI into the HHS long-term services initiatives, which also rely on Aging and Disability Resource Centers (ADRCs) as the entry point into these systems;

2. promote collaboration with the Administration on Aging (AoA) on falls related TBIs among older adults, a major cause of TBI;

3. include TBI in the veterans initiatives between HHS and Department of Veterans Affairs to support Home and Community-Based Services (HCBS) for veterans and returning servicemembers coordinated by the ACL's Office of Disability and Aging Policy's Office of Integrated Programs;

4. coordinate and enhance services for individuals with TBI who could benefit from the ACL's Administration on Intellectual/Developmental Disabilities (AIDD) initiatives to improve education, transition services, employment outcomes and self-advocacy for children and youth;

5. include TBI in the Office of Disability and Aging Policy's Office of Integrated Policy initiatives (i.e. Lifespan Respite Care Program, Participant Direction Program, Evidenced-Based Care Transitions, and Transportation Research and Demonstration Program);

6. include families providing caregiving services to their family members with TBI in the Lifespan Respite Care Program, and

7. further collaborate with other programs transferred to the ACL through the Workforce Innovation and Opportunity Act including the Assistive Technology, Independent Living and the National Institute on Disability, Independent Living, and Rehabilitation Research (formerly NIDRR) TBI Model Systems programs.

As directed by the Olmstead Decision, States are expanding community long-term services options for individuals with disabilities or who are aging. Unfortunately, most States focus on the traditional populations of I/DD, physical disabilities, aging and mental health and are omitting TBI in their long-term care initiatives. This leaves individuals with TBI with little options, other than nursing facilities or other segregated living programs, for assistance with activities of daily living and residential or housing needs. We believe that aligning the Federal TBI State Grant Program with these other ACL programs focusing on HCBS initiatives will help address these concerns.

The TBI Act is the *only* federal legislation providing assistance to help States with developing an array of rehabilitation, home and community-based services and supports specific to the cognitive and behavioral needs of individuals with TBI. Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory, although not concurrently, to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Only 20 States currently receive federal grant funding. **Therefore, we believe it is imperative to position the program within ACL that will foster collaboration and coordination of resources to assist all States and Territories.**

NASHIA is well aware that federal funds are becoming increasingly difficult to obtain, let alone being increased, therefore NASHIA is recommending relocating the program because:

- The number of Americans who sustain a TBI is increasing, especially among older adults and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan.

- All States have enacted legislation to develop return to play guidelines with regard to sports-related concussions among our youth. Through these efforts, children and youth are now being identified and screened for potential assistance. However, after the age of 21, few will have resources available to them once they are no longer eligible for children's services.
- State budgets have not been able to keep up with the demand for services.

In closing, NASHIA is a non-profit organization representing and assisting State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families. These officials are employed by State public health, Vocational Rehabilitation, mental health, Medicaid, intellectual/developmental disabilities, education and social services agencies. Over the past thirty years, State TBI programs have emerged to address an array of needs including, information and referral, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI to live, work and return to school following a brain injury, as well as supports to assist their families with caregiving. These services vary in size and scope across the country and even within a State, in part, due to lack of sufficient funding.

A few States receive state funds (general revenue) to pay for services, while other States cover services under the Medicaid State Plan or Medicaid Home and Community-Based Waiver Programs, or dedicated funding largely from traffic fines or may use a combination of funding sources to pay for necessary services. Not quite half

of the States have enacted legislation to assess additional fines or surcharges to traffic related offenses or other criminal offenses and/or assessed additional fees to motor vehicle registration or drivers license to generate funding for TBI programs and services, generally referred to as a trust fund program. States are currently administering 27 TBI Home and Community-Based Medicaid Waiver Programs for individuals with brain injury who are Medicaid eligible with a few States administering more than one brain injury waiver program within their State.

The federal TBI State Grant Program has helped States to plan, develop, expand and improve services to better address the array of needs for individuals of all ages, regardless of cause of injury, including military-related injuries, sports-related concussions, and victims of domestic violence. By partnering with ACL programs, we believe additional federal resources can be accessed to further address the growing needs and help States which have limited State resources.

Should you wish additional information, please do not hesitate to contact Rebecca Wolfkiel, Governmental Consultant, at 202-480-8901 (office) or 717-250-6796 (cell) or email: [rwolfkiel@ridgepolicygroup.com](mailto:rwolfkiel@ridgepolicygroup.com). You may also contact Susan L. Vaughn, Director of Public Policy, at 573-636-6946 or [publicpolicy@nashia.org](mailto:publicpolicy@nashia.org) or William A.B. Ditto, Chair of the Public Policy Committee, at [williamabditto@aol.com](mailto:williamabditto@aol.com).

Thank you.

**Jim Maddy, President and CEO**  
**Association of Zoos and Aquariums**  
**Testimony – House Subcommittee on Labor, Health and Human Services, Education and**  
**Related Agencies**

Thank you Chairman Cole and Ranking Member DeLauro for allowing me to submit testimony on behalf of the nation's 215 AZA-accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of \$38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the FY2016 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501c(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. AZA-accredited zoos and aquariums annually see more than 180 million visitors, collectively generate more than \$17 billion in annual economic activity, and support more than 165,000 jobs across the country. Over the last five years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with \$160,000,000 annually in more than 100 countries. In the last 10 years, AZA-accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the "Museum and Library Services Act of 2003" (P.L. 108-81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and

scientific heritages. Grants are awarded in several areas including educational programming, professional development, and collections management, among others.

As valued members of local communities, AZA-accredited zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services assure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Despite this funding shortfall, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever. AZA-accredited zoos and aquariums are essential partners at the federal, state, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, AZA-accredited zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the nation's economic and cultural vitality. Therefore, I strongly encourage you to include \$38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the FY2016 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.



## COUNCIL OF ACADEMIC FAMILY MEDICINE

Association of Departments of Family Medicine  
 Association of Family Medicine Residency Directors  
 North American Primary Care Research Group  
 Society of Teachers of Family Medicine



Tom Campbell, MD

Chair, Council of Academic Family Medicine

*Submitted for the Record to the House Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies –*

*Apr 29, 2014*

### FY 2016 FUNDING REQUESTS

We urge the Committee to appropriate at least \$71 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act, and appropriate \$287 million for the National Health Service Corps (NHSC,) both under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than \$375 million in base discretionary funding to support research vital to primary care.

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The programs we support in our testimony are ones that deliver an investment in our nation's workforce and health infrastructure. They are a down payment on a US health care system with a foundation of primary care that will produce better health outcomes and help reduce the ever rising costs of health care. We understand that hard decisions must be made in these difficult fiscal times, but even in this climate, we hope the Committee will recognize that the production of a robust primary care workforce for the future is a necessary investment that cannot wait and will ultimately produce long term savings.

### ***Primary Care Training and Enhancement***

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of providing indispensable funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and research critical to primary care delivery, as well as innovations in team management of chronic disease, integrated models of care, and transitioning between health care settings.

As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will need to rely even more on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. This is even more so with the passage of the Medicare Access and Chip Reauthorization Act (MACRA) which changes Medicare payment methodologies to incentivize alternatives to traditional fee for service. Some areas in need of support for future training include: training in clinical environments that are transforming or have transformed to include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in interprofessional teams that include diverse professions outside of medicine; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies will be required for our developing health system. The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that “[r]esources

currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes.”<sup>i</sup>

In order to address some of these challenges, the Advisory Committee recommends that Congress increase funding levels for training under the primary care training health professions program, both in FY2016 and for the next five years. The current funding level (approximately \$38.9 million) is not enough to allow for the pent up demand caused by reduced and stagnant funding levels.

Primary care health professions training grants under Title VII continue to have a profound impact on states across the country and are vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We urge your continued support for this program and an increase in funding to \$71 million in FY2016 to allow for a robust competitive funding cycle.

### ***National Health Service Corps***

The NHSC recruits and places physicians and medical professionals in health professional shortage areas to meet the need for health care in rural and medically underserved areas. The NHSC provides scholarships or loan repayments as incentives for medical students to enter primary care and to provide health care to underserved Americans. By addressing medical school debt burdens, the NHSC also ensures wider access to medical education opportunities.

Since in 1972, the NHSC has offered financial assistance to recruit and retain health care providers to meet the workforce needs of communities across the nation designated as health professional shortage areas (HPSA). The Government Accountability Office (GAO-01-1042T) described the NHSC as “one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas.” More than 40,000 providers have served in the NHSC since its inception. In FY 2014, the NHSC had a field strength of 9,242 primary care clinicians. NHSC physicians and health care providers were placed in HPSAs serving patients in every state and territory. Our total funding request would increase the field strength to over 15,000

Corps members, serving nearly 16 million patients. We are concerned that by not having funding in the appropriations baseline, the program could face another funding cliff when the current mandatory funds expire.

***Agency for Health Care Research and Quality (AHRQ)***

We are grateful that Congress included budget authority for AHRQ in the FY15 omnibus funding bill, and would like to thank the committee for including it in the funding bill. This change strengthens the viability of an agency that is vital to the development of primary care research and implementation of such research into primary care practice around the country. The majority of research funding in the United States supports research of one specific disease, organ system, cellular, or chemical process – not for primary care. This is in spite of the fact that the overall health of a population is directly linked to the strength of its primary health care system. Primary care research includes: translating science into the practice of medicine and caring for patients, understanding how to better organize health care to meet patient and population needs, evaluating innovations to provide the best health care to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

There are six areas that we believe AHRQ excels at – and that are not available elsewhere in the biomedical research infrastructure: primary care research through Practice-based Research Networks (PBRNs), practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, mental and behavioral health provision in communities and primary care practices, and training future primary care investigators. Critical to the successful engagement and development of primary care research is the constraint of not having an adequate cadre of well-trained researchers. We believe there is a need to deliberately promote this training as a way to aid in the development of all the areas we have emphasized. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded.

Below are some examples of the work of AHRQ that have been instrumental in supporting primary care practice and patient safety:

- One of AHRQ's new funding initiatives in the coming year is for research into multiple chronic conditions -- a hallmark of primary care practice. These grants are directed to 1) provide clinicians with tools to develop integrated care plans that reflect patients' conditions, values, preferences, etc., and 2) data to examine the impact of integrated care plans and new care models on utilization and quality of care. Additionally, funding will be used for data collection to identify how health care teams are organized and if care and outcomes look different in team based practices, compared to traditional practices.
- Highlighting the success of AHRQ's patient safety initiatives, a 2014<sup>i</sup> report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17% in hospital-acquired conditions. Additionally, the report enumerated a decline in harm to patients of over 1.3 million, 50,000 lives saved, and \$12 billion in reduced health spending during that period.

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians treat is lacking. AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. This research is essential to create a robust primary care system for our nation -- one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. This type of research requires sufficient funding for AHRQ, so it can help researchers address the problems confronting our health system today.

**We recommend the Committee fund AHRQ at a base, discretionary level of at least \$375 million for Fiscal Year 2015.**

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<sup>i</sup> <http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>

<sup>ii</sup> Publication # 15-0011-EF

**Written Statement of Jeffrey Levi**  
**Executive Director, Trust for America's Health**  
**House Appropriations Subcommittee on Labor, Health & Human Services, Education and**  
**Related Agencies**

Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority, is pleased for this opportunity to provide written testimony on the state of public health funding. As this subcommittee works to develop a FY2016 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to ensure adequate funding for public health, prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

Every American should have the opportunity to be as healthy as he or she can be, but right now, Americans are not as healthy as they could or should be. The effects of sequestration and years of funding cuts have fundamentally eroded our ability to respond to disasters, prevent chronic diseases, reduce health disparities, and ensure the health of all Americans. Preventable chronic diseases such as cancer, diabetes, lung disease, heart disease and stroke are responsible for seven out of 10 deaths and cost \$1.3 trillion in treatment costs and lost productivity every year. We were pleased that Congress made important new investments in community prevention over the past two fiscal years that will help continue our efforts to transform our health care system to one that values prevention and wellness and urge the Committee to build on those investments in the FY2016 bill.

In 2014 the nation saw the first domestic cases of Ebola virus and chikungunya, multi-state cyclospora and measles outbreaks, severe cold and drought, wildfires, tornados, and mudslides. These events illustrated persistent gaps in the country's preparedness for diseases, disasters, and bioterrorism. Each of these required a public health and healthcare response, but federal, state, and local budget cuts have threatened more than a decade of progress.

Finally, prescription drug abuse has quickly grown into a full-blown epidemic, with more than 6.1 million Americans abusing or misusing prescription drugs. Overdose deaths from prescription drugs have quadrupled since 1999 and outnumber deaths from all illicit drugs combined. Addressing this epidemic requires investments in prevention and treatment of those suffering from substance abuse addiction.

Building a public health system prepared to meet the challenges of protecting Americans from natural and man-made threats and preventing disease can only occur with a strong and steady baseline of funding. Below are TFAH's recommendations for meeting that challenge:

#### **The Prevention and Public Health Fund (PPHF)**

**TFAH was pleased to see Congress exercise its authority to allocate the Prevention and Public Health Fund in FY 2014 and FY 2015, and we urge the Committee to do so again in the FY 2016 appropriations bill.** To date, the Fund has invested nearly \$5.25 billion nationwide to support state and local efforts to transform communities, build epidemiology and laboratory capacity, address healthcare associated infections, train the nation's public health and health workforce, screen for and prevent cancer, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

#### **Centers for Disease Control and Prevention (CDC)**

From FY 2010 to 2013, the CDC saw its budget authority cut by 18 percent. The FY 2015 Omnibus Appropriations measure provided CDC with an increase of about \$43 million, including \$887.3 million from the Prevention and Public Health Fund, resulting in an overall near \$13 million increase for chronic disease programs, which brought funding back to FY 2013 levels. Scarce resources means CDC will be forced to make extremely difficult choices. **We urge the Committee to support the overall \$110 million program level increase included in the President's budget for FY 2016.**

**National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) –**

**CDC**

We must continue to engage not only health systems but sectors such as education, housing, business, planning, and faith-based institutions to help communities to make the healthy choice the easy choice. CDC's Chronic Disease Center has made progress in moving away from the traditional categorical approach to funding disease prevention and toward more coordinated, cross-cutting strategies. **We encourage the Committee to fund the Chronic Disease Center at FY 2015 levels (\$1.198 billion), building upon FY2015 investments in diabetes, heart disease and stroke, the Partnerships to Improve Community Health initiative, the Racial and Ethnic Approaches to Community Health program and the Preventive Health and Health Services Block Grant program.** TFAH calls upon the Committee to promote the Prevent Block Grant's use to modernize our public health system by supporting health department accreditation to ensure the nation's health departments can deliver foundational public health capabilities to all Americans.

**National Center for Environmental Health (NCEH) – CDC**

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. Yet it remains one of the most critically underfunded parts of CDC. **We recommend that you fund NCEH at \$212.460 million in FY2016** to maintain and grow the National Environmental Public Health Tracking Network (by \$5 million), expand the Climate and Health program to all 50 states, fully restore the Childhood Lead Poisoning Prevention Program, and pursue other important priorities like asthma control and the built environment.

**Public Health Emergency Preparedness (PHEP) Cooperative Agreements – CDC**



The Public Health Emergency Preparedness (PHEP) cooperative agreements, administered by CDC, is the only federal program that supports the work of state and local health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The program has been integral in building preparedness capabilities since 2001, but unreliable federal funding places Americans at risk. **TFAH recommends \$675 million for the Public Health Emergency Preparedness Cooperative Agreements in FY2016**, a \$31 million increase, to help states and localities restore some of the core capabilities lost due to significant cuts in recent years.

#### **Hospital Preparedness Program – ASPR**

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides funding and technical assistance to prepare the health system to respond to and recover from a disaster. HPP is building the capacity of 24,000 healthcare coalitions – regional collaborations between healthcare organizations, providers, emergency managers, public sector agencies, and other private partners – to meet the disaster healthcare needs of communities. HPP helped save lives during recent events, including the Boston Marathon bombings. HPP appropriations have decreased from \$426 million in FY10 to \$255 million in FY2015, including a one third cut in the FY2014 omnibus. Cuts have resulted in reduced capabilities in areas such as planning, exercises, management of supplies, and preparedness training. **TFAH recommends \$300 million for FY2016 for HPP, an incremental step toward rebuilding the program.**

#### **Combating Prescription Drug Abuse – CDC & SAMHSA**

TFAH was pleased the President's budget included \$133 million in new investments to address prescription drug abuse, heroin use and overdose deaths, including new funding for the CDC and the Substance Abuse and Mental Health Services Administration (SAMHSA). TFAH

strongly supports this cross-government initiative. **TFAH supports the President's budget request for \$68 million (a \$48 million increase) for the CDC Injury Center's Injury Prevention Activities line** to enable the CDC to expand its work to all 50 states to help address the epidemic of prescription drug overdoses and provide states with additional resources for surveillance and prevention efforts. Prescription drug abuse is a national problem requiring a national response.

**TFAH also supports the request for \$12 million for SAMHSA to establish the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (PDO) program**, which will provide grants to 10 states to reduce significantly the number of opioid overdose-related deaths. **TFAH supports \$25 million (a \$13 million increase) for SAMHSA to expand access to medication assisted treatment**, which is currently unavailable for many Americans who desperately need it. Additionally, **TFAH recommends a \$25 million increase for the Substance Abuse Block Grant (SABG) to help expand access to substance abuse treatment**. While there has been more than a five-fold increase in treatment admissions in the past decade, millions more are going untreated. The SABG alone accounts for about 40% of spending by state substance abuse agencies, yet it has been level funded at \$1.8 billion despite the increased burden of addiction.

### **Conclusion**

Eighty-five percent of the CDC's annual budget flows to states, communities, tribes, and territories in the form of grants and contracts to state and local public health departments, and community partners to give them the tools they need to conduct critical public health and prevention activities, such as protecting us from infectious diseases by combating healthcare-associated infections by delivering immunizations, ensuring adequate public health emergency preparedness, and conducting nonstop disease surveillance. Investing in disease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Thank you for your consideration.

TO: U.S. House of Representatives, Health & Human Services Appropriations Subcommittee  
 FROM: Trish Carney, Finance Director, Heightened Independence and Progress  
 RE: FY 2016 Written Testimony for the Record

As the Finance Director of Heightened Independence and Progress, which administers two Centers for Independent Living in New Jersey, I am writing to support the National Council on Independent Living's request for Congress to reaffirm its commitment to the more than 57 million Americans who have disabilities by increasing funding in the HHS budget for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$306 million for the Independent Living line item in FY 2016.

In 2015 we are receiving \$256,589 from RSA (now transitioned to HHS) for one of our Centers. In 2008 we received \$255,397. Our other Center is receiving \$251,357 this year; in 2008 it received \$250,190. Do the math - this is an increase of \$1,192 and \$1,167 respectively – IN THE COURSE OF SEVEN YEARS!!!! This doesn't even come close to how much the cost of living has increased in this time. Rent, utilities, gas, food - you name it – have certainly increased much more than that in seven years. Raises are virtually non-existent – and with ever-increasing medical costs staff is actually losing money while we are actually saving the government money as we provide services that enable people with disabilities to remain in the community rather than relocate to more expensive institutional settings.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 356 federally

funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and the newly added transition services. From 2012-2014, CILs provided the four core service to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals.

Transition services were added as a fifth core service with the passage of the Workforce Innovation and Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their

understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2015, the Independent Living Program is receiving nearly \$3 million less in funding than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.



April 28, 2015

The Honorable Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

The Honorable Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of Best Buddies International, Inc. and the community of individuals with intellectual and developmental disabilities that we serve, I write to express our strong support for continued appropriations to the Department of Health and Human Services for activities promoting community integration for individuals with disabilities.

Best Buddies is a 501(c)3 non-profit organization that works to enhance the lives of individuals with intellectual and developmental disabilities through one-to-one friendships with typical peers, integrated employment, and leadership development. I founded Best Buddies at Georgetown University in 1989 on the premise that one-to-one friendships between people with and without IDD could lead to a truly inclusive society where individuals are recognized for their unique skills and talents, and the social chasm between people with and without IDD could be permanently bridged. We have grown from one original chapter to more than 1,900 chapters on middle school, high school, and college campuses and reach participants in all 50 states and over 50 nations. For 25 years, we have worked to improve and expand the inclusion movement, and we currently impact 900,000 people worldwide through our eight formal programs.

The activities of the Department of Health and Human Services are widely supported by both Best Buddies and our constituents and are critically important to improving the lives, independence and well-being of individuals with disabilities. We understand that one organization has urged its members to demand language in the Labor, Health and Human Services, Education and Related Agencies appropriations bill that would prohibit the use of funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is extremely troubling and counter to the Supreme Court's landmark decision in *Olmstead v. L.C.*, often referred to as the *Brown v. Board of Education* of the disability community.

Enforcement of the Americans with Disabilities Act integration mandate and the *Olmstead* decision is a top priority for the disability community. In recent years, *Olmstead* enforcement efforts have brought some of the most significant improvements to the lives of people with disabilities in decades. Thousands of individuals with disabilities have, for the first time, been given opportunities to live in their own homes and communities, with privacy, dignity, and independence. They have been able to participate as full members of society.

HEADQUARTERS | 100 Southeast Second Street | Suite 2200 | Miami, Florida 33131 | 305.374.2233 | FAX 305.374.5305  
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***Friends and Jobs – the Ticket to Success!***

*The Honorable Tom Cole*  
*April 28, 2015*  
*Page Two*

Similarly, implementation of the new rules concerning Medicaid-financed home and community-based services is important to ensure that disability service systems support the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Neither *Olmstead* enforcement nor implementation of the Medicaid home and community-based services rules deprives anyone of the choice to live in an institution. To the contrary, *Olmstead* and the Medicaid rules offer thousands of individuals and their families the option of choosing home and community-based service settings—an option that has been unavailable for far too long. No one is forced to move to a community setting against his or her wishes.

Inclusion of any language prohibiting use of congressional appropriations for enforcement of regulations governing home and community based service settings would deprive people with disabilities of choice and force them to live and receive services in restricted and segregated settings. We urge you not to include this language in the appropriations bill. People with disabilities have fought hard for decades for the opportunity to live, work, and receive services in integrated settings.

Sincerely,



Anthony K. Shriver  
Chairman

**A.E. MACHAK**  
**2400 PEARSON PARKWAY**  
**WAINWRIGHT, IL 60095-7632**

Aloysius E. Machak

Secretary

Friends of Ann Kiley Center, Inc. (501 C-3 not-for-profit fund-raising

I write to your committee's sub-committee on Labor regarding hearings being held by that body on Fiscal Year 2016 appropriations, specifically that section dealing with the various agencies which are now and will be in the coming year actively engaged in attempting to effect deinstitutionalization of state-operated facilities for developmentally and intellectually disabled individuals. Nowhere in its Olmstead decision does the United States Supreme Court mandate the closure of such facilities; in fact, the Court has held that different levels of care will require a diversity of programs and indeed some of those programs may well be better served (as they are now) in the existing state facilities. Too, the decision of choice for which facility best ~~meet~~ the needs of the individuals served belongs to the court-appointed guardians (even in the case of the state guardians where such is the case of guardianship).

Now organizations like Equip for Equality, an agency created by the Americans With Disabilities funded by Federal dollars with its formidable array of pro bono lawyers is reading into the Olmstead decision something was never intended. Here in Illinois this activity has cost parents and guardians thousands of dollars for legal fees to fight the closure of one and another in process state-operated facilities. E for E pushes for all present residents in SOD settings should and would be better off in a community setting. What is most unconscionable is the use of half-truths, apple versus oranges statistical comparisons, cost comparison studies which leave out references to any value associated with state operated facilities so as to sway legislators to their way of thinking.



As strongly as Equip for Equality closure proponents feel about their position, I feel even stronger about the ~~benefits~~ of state operated centers. Our son, now 51 years old lived at home for the first twenty two years of his life. He had attended a private facility from age seven until his twenty second birthday. They would no longer take Richard because of his behavior. At home he became aggressive to family and himself. Life was unbearable except when a respite person came for two hours. He suggested a behavior alteration program.....At Howe Center in Tinley Park Illinois. After nine months he came home a different person. Yes, Howe Center was a state-operated facility, now closed. What to do with Richard. Kiley Center is five blocks from our home. We didn't want to send him there; some bad stories about neglect and abuse had been widely circulated in our local newspaper. The facility ~~director~~ said "Give Kiley a chance, Don't Believe everything you read in the papers". He was right. Since 1985 Richard has called Kiley Center home. He is exposed a full array of services including going to workshop off campus. He is a regular visitor at home almost every Sunday. His campus is composed of 47 duplex cottages and except for the bedrooms being all on one side of the house, it is like any other duplex.....not a warehouse by any stretch of the imagination.

You can get similar stories from parents and guardians about their own family member's backgrounds. Closing a place like Kiley is a step backward in the residents' lives. It's unfortunate we must continue to fight so hard to keep it open.. ..... "One size does not fit all" even in the area of developmental disability!

Thank you

*Aloysius E. Mackus*



#### Easter Seals

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**Outside Witness Testimony**  
**U.S. House of Representatives Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**Submitted by:**  
**Jennifer Dexter**  
**Assistant Vice President, Government Relations**  
**Easter Seals**

**April 29, 2015**

Easter Seals respectfully asks that you make funding for federal programs that help people with disabilities, older adults and veteran families reach their potential and fully participate in their communities a top priority within your fiscal year (FY) 2016 Labor, Health and Human Services, Education and Related Agencies appropriations bill.

For nearly 100 years, Easter Seals has helped individuals from across the country remove significant barriers to their ability to thrive in their communities through evidence-based services funded through key federal programs. Easter Seals supports all federal programs that make a difference in the lives of the individuals and families we serve. We have prioritized the following programs for you to consider in FY 2016. Your support for these federal programs is critical in our ability to, for example, **help a young child** meet developmental milestones—**assist a jobseeker** in developing new skills to find meaningful employment — **empower a student with a disability** by connecting the young person to public transportation and travel training in their community —**train a veteran caregiver** with the specialized skills to help best care for their loved one who was injured during their military service to our nation.

Labor, Health and Human Services, Education and Related Agencies

- **Community Service Employment for Older Americans (U.S. Department of Labor)**  
*Easter Seals FY 2016 Request: No less than \$445,500,000 (minimum)*  
*President's FY 2016 Request: \$434,371,000*  
*FY 2015 Enacted: \$434,371,000*

Title V of the Older Americans Act authorizes the Community Service Employment for Older Americans program (also known as the Senior Community Service Employment Program or SCSEP) to assist unemployed, low-income older adults return to unsubsidized employment through paid, work-based training at non-profit and public facilities. Through the program, SCSEP participants earn wages (federal or state minimum wage, whichever is higher) while they earn new skills and work experience.

Seventy five percent of the federal SCSEP funds are spent on participant training wages and benefits.<sup>i</sup> As a result of the November elections and state legislative decisions, the minimum wage increased in more than 20 states at the beginning of 2015, with the average increase among the states recorded at 50 cents an hour.<sup>ii</sup> These new minimum wages will mean larger training paychecks for SCSEP participants in those states. However without additional federal funding for SCSEP, the state minimum wage increases will mean fewer older workers will benefit from the effective work-based training. Easter Seals estimates an additional \$11 million above the Administration's FY 2016 SCSEP budget request will be required to ensure the same number of older workers is served through the program as a result of the training wage increases.

- **Early Intervention Grants for Infants and Families (U.S. Department of Education)**

*Easter Seals FY 2016 Request: \$503,556,000*

*President's FY 2016 Request: \$503,556,000*

*FY 2015 Enacted: \$438,556,000*

Early diagnosis of developmental delays and timely intervention services for young children are critical in a child's long-term development and success. As the largest provider of early intervention services, Easter Seals knows what is possible when kids get the support they need and what happens when they do not. The Early Intervention Grants for Infants and Families program (also known as Part C of the Individuals with Disabilities Education Act) provides formula grants to all 50 states to assist them in implementing statewide systems of coordinated, comprehensive, multidisciplinary, interagency programs and making early intervention services available to children with disabilities, aged birth through 2, and their families. The American Academy of Pediatrics reports the prevalence of childhood disability continues to increase, growing by more than 15 percent between 2001 and 2010, yet the early intervention program is now serving nearly 5 percent fewer children in 2013 than in 2010. As a result of stagnant federal funds, states have modified their program so that fewer children are eligible for support. Easter Seals supports the Administration's FY 2016 budget request that would increase the average state award by approximately \$945,000 over last year's level to allow states to enhance their early intervention systems and increase services.<sup>iii</sup>

**Preschool Grants for Children with Disabilities**

*Easter Seals FY 2016 Request: \$403,238,000*

*President's FY 2016 Request: \$403,238,000*

*FY 2015 Enacted: \$353,238,000*

The Individuals with Disabilities Education Act (IDEA) has a program to support the educational needs of children between the ages of 3 and 5 years who have disabilities and also require special education services. IDEA affords these children the same right to a free, appropriate, public education that is guaranteed under IDEA to students in elementary and secondary education. When Congress established the IDEA preschool program in 1986, it set a goal of providing \$1500 to states for each eligible child. The FY 2013 appropriation provided \$471 per child, The President's request would raise this amount to \$541. Overall funding for the Preschool program has been stagnant since 2008, with real cuts to the program beginning in 2013.

- **Homeless Veterans' Reintegration Program (U.S. Department of Labor)**

*Easter Seals FY 2016 Request: \$50,000,000 + Report Language (below)*

*President's FY 2016 Request: \$38,109,000*

*FY 2015 Enacted: \$38,109,000*

The Homeless Veterans' Reintegration Program (HVRP) is the only federal nationwide program focused exclusively on the employment of veterans who are homeless. Through the program, community-based organizations, including non-profits and faith-based groups, provide job training, counseling, and placement services to help homeless veterans reintegrate into society and the labor force. About 17,000 homeless veterans in nearly 150 communities across the country benefit each year from HVRP's specialized skills training and personalized connections to other community services.<sup>iv</sup> HVRP has been an important tool in helping to decrease veterans' homelessness by 33 percent or 24,837 veterans since 2010.<sup>v</sup> Full funding for HVRP is needed now more than ever to ensure the nearly 25,000 formerly homeless veterans retain their jobs and to meet the needs of the remaining population of homeless veterans. Congress has authorized HVRP at \$50 million in the past. Easter Seals requests full funding at \$50 million in FY 2016 to allow HVRP to serve more veterans, keep up with increased training and related costs, and pilot innovative strategies, including the use of regional and multi-state awards, to increase service delivery efficiencies and improve outcomes.

Easter Seals requests the following report language be added in the FY 2016 bill: *"The Committee recognizes the role of HVRP in decreasing veterans' homelessness by helping homeless veterans or veterans who are at risk of homelessness through job training, counseling, and placement services. Within the increase provided for HVRP, the Committee directs the Secretary of Labor to conduct a pilot to demonstrate the use of regional and/or multistate awards to national organizations to test service delivery efficiencies and improved outcomes."*

<sup>i</sup> U.S. DOL FY 2016 SCSEP Budget Request: <http://www.dol.gov/dol/budget/2016/PDF/CBJ-2016-V1-06.pdf>

<sup>ii</sup> The PEW Charitable Trusts' Stateline Article: <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/1/06/where-minimum-wage-workers-will-earn-more-this-year>

<sup>iii</sup> U.S. DoED FY 2016 Budget Request: <http://www2.ed.gov/about/overview/budget/budget16/justifications/i-specialied.pdf>

<sup>iv</sup> U.S. DOL FY 2016 Budget Request: <http://www.dol.gov/dol/budget/2016/PDF/CBJ-2016-V3-05.pdf>

<sup>v</sup> HUD/VA Report: [http://portal.hud.gov/hudportal/HUD?src=/press/press\\_releases\\_media\\_advisories/2014/HUDNo\\_14-103](http://portal.hud.gov/hudportal/HUD?src=/press/press_releases_media_advisories/2014/HUDNo_14-103)

Prostatitis Foundation -  
Promoting Education & Research  
1063 30<sup>th</sup> Street -  
Smithshire, IL 61478



Check the internet  
and see the  
world wide web page:  
<http://www.prostatitis.org>

Submitted by: Mike Hennenfent, President of the Prostatitis Foundation

FY 2016 written testimony for the record.

The Prostatitis Foundation requests the Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies, to increase their funding for prostatitis research. The NIDDK's Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network encompasses Prostatitis and related disease. This ongoing, twenty year research effort should be funded to completion. Finding the cause and cure are long overdue. Only the NIH can decide how much money can be used efficiently for this research completion.

Prostatitis or Chronic Pelvic Pain Syndrome (CPPS) has been a scourge to mankind for many years. At one International Convention of the American Urological Association the physician speaking said Chronic Prostatitis was as painful to the doctor as the patient. That is because the doctor knew he could do little to alleviate the symptoms of the patient and the patient would return over and over again with more complaints. Prostatitis is not a new disease. It is seldom discussed publicly because of an assumed stigma by some patients. Tony Fadell (a West Coast Entrepreneur) is reported to have said, "It is easy to cure a problem that everyone sees, but it's much harder to solve a problem that almost no one sees." He was not speaking to this issue but it sure applies to prostatitis.

The cure has been elusive as far back as Napoleon according to some medical historians. In Napoleon's battles and conquests he had to stand in a chariot rather than ride a horse it was noted. Napoleon has been quoted as having said something to the effect that doctors and

**The Prostatitis Foundation does not endorse any medicine, doctor, or treatment protocol.**

generals will have much to account for on the final day of judgement. John Kennedy was reported by Readers Digest to have prostatitis. Will Durant spoke about his travails with prostatitis in his autobiography.

Because of persistent efforts by the NIH light is being focused on the problem of prostatitis but a cure has been elusive. Many or most of the common treatments have not stood up to clinical trials. It is critical that the information gathered in the past and the research groups now in place are adequately funded to utilize the work already done and preserve any information produced thus far. Keep in mind that because of anxiety, sexual dysfunction & disability many patients are unable to work. Prostatitis has an effect on the whole family.

These research funds need to be increased as the costs of prostatitis are substantial and knowing the cause and prevention would provide huge savings in the future.

Prostatitis Foundation

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[www.prostatitis.org](http://www.prostatitis.org)

**TESTIMONY OF  
HAROLD BROOKS, SENIOR VICE PRESIDENT  
OF INTERNATIONAL OPERATIONS  
THE AMERICAN NATIONAL RED CROSS**

**AND ON BEHALF OF  
KATHY CALVIN, PRESIDENT  
UNITED NATIONS FOUNDATION**

**IN SUPPORT OF FUNDING FOR THE CENTERS FOR DISEASE CONTROL AND  
PREVENTION (CDC)**

**APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**UNITED STATES HOUSE OF REPRESENTATIVES  
April 21, 2015**

Chairman Tom Cole, Ranking Member Rosa DeLauro, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles regional elimination activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles regional elimination.

In 2001, CDC – along with the American Red Cross, the United Nations Foundation, the World Health Organization (WHO), and UNICEF – founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative. In 2013, all WHO regions established measles elimination goals by 2020. The Measles & Rubella Initiative is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved impressive results by supporting the vaccination of more than 1.8 billion children since 2001. Largely due to the Measles & Rubella Initiative, global measles mortality dropped 75%, from an estimated 548,000 deaths in 2000 to 145,700 in 2013 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 88%. About 400 children still die from measles each day from a virus that can be countered with a safe, effective and inexpensive vaccine. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished. Measles spreads much more easily than the flu or the Ebola virus. In fact, one person infected with measles can infect up to 18 others if he has not been vaccinated. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS can cause severe birth defects, including

blindness, deafness, heart defects and mental retardation. CRS treatment is very costly, yet very inexpensive to prevent.

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$1.3 billion and provided technical support in more than 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2013, an estimated 15.6 million measles deaths were averted as a result of these accelerated measles control activities, making measles mortality reduction one of the most cost-effective public health interventions.

The majority of measles vaccination campaigns have been able to reach more than 90% of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. Doses of oral polio vaccine are frequently distributed during measles campaigns in polio endemic and high risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

The extraordinary reduction in global measles deaths greatly contributed to reducing under-five child mortality. However, large outbreaks in several African, European and Asian countries from 2011 to 2014 have compromised 2015 measles elimination goals. These outbreaks highlight the fragility of the last decade of progress. If mass immunization campaigns are not continued, measles deaths will rapidly increase.

To achieve the 2020 elimination goals and avoid a resurgence of measles, the following actions are required:

- Fully implementing activities, both campaigns and strengthening routine measles coverage, in India since it is the greatest contributor to the global burden of measles and congenital rubella syndrome though surveillance is weak in recording the latter.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90% of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
- Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from Gavi, the Vaccine Alliance.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. The Measles & Rubella Initiative faces a funding shortfall of an estimated



US \$368.8 million for 2015-2020. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95%.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. adults and children are also being protected from the diseases. Measles can cause severe complications such as pneumonia, encephalitis, and even death. Endemic transmission of measles cases have been eliminated in the United States since 2000 and rubella since 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from a low of 37 in 2004 to a high of 664 people across 27 states in 2014; the greatest number of cases reported in the U.S. since measles was declared eliminated in 2000. This country is experiencing a large, multi-state outbreak of measles. The financial impact of these cases and outbreaks are substantial, both in terms of the costs to public health departments to conduct contact tracing and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between \$100,000 and \$200,000 to control.

### **The Role of CDC in Global Measles Mortality Reduction**

Since FY 2001 and until 2015, Congress has provided funding for the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 88 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support – made possible by the funding appropriated by Congress – was essential in helping achieve the sharp reduction in measles deaths in just thirteen years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate to have a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In FY 2014 and FY 2015, Congress appropriated \$49.8 million each year to fund CDC for global measles control activities. In FY 2016, the American Red Cross and the United Nations Foundation request sustained funding at the level requested by the President, \$49.8 million for CDC's measles and rubella control activities to protect the investment of the last decade and prevent a global resurgence of measles.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.



**Testimony Prepared by Alberto Cortés, Executive Director of Mama's Kitchen for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Mama's Kitchen is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 350,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease,

cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public

insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more

expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

### **Conclusion**

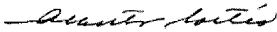
We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of

new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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<sup>i</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

<sup>ii</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>iii</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>iv</sup> Ibid.

<sup>v</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

<sup>vi</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

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National Association of County & City Health Officials

*The National Connection for Local Public Health*

**Statement of the  
NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS  
1100 17<sup>th</sup> St. NW, 7<sup>th</sup> Floor  
Washington, DC 20036**

**Submitted for the record to the Subcommittee on Labor, Health and Human  
Services and Education, Committee on Appropriations  
United States House of Representatives**

**FY 2016 Appropriations for Programs at the Department of Health and Human Services**

**Contact:**     *Eli Briggs, NACCHO Senior Government Affairs Director*  
202-507-4194/[ebiggs@naccho.org](mailto:ebiggs@naccho.org)

The National Association of County and City Health Officials (NACCHO) is the voice of the 2,800 local health departments across the country. City, county, metropolitan, district, and tribal health departments work daily to ensure the safety of the water we drink, the food we eat, and the air we breathe. On behalf of local health departments, NACCHO submits the following requests:

***Public Health Emergency Preparedness – Centers for Disease Control and Prevention (CDC)***

NACCHO urges the Subcommittee to provide \$675 million for the Public Health Emergency Preparedness (PHEP) cooperative agreements in FY2016. Recently, local health departments have responded to the threat of infectious diseases like Ebola and measles and more severe and frequent weather events causing natural disasters. Emergency federal funding to respond to the unexpected threat of Ebola is much appreciated. However, sustained funding to support local preparedness and response capacity is needed to make sure that every community is ready for any disaster it may confront. A majority of local health departments rely solely on federal funding for emergency preparedness. PHEP protects communities by providing funding to strengthen local and state public health departments' capacity and capability to effectively

respond to public health emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies.

***Hospital Preparedness Program – Assistant Secretary for Preparedness and Response (ASPR)***

The experience of responding to Ebola shows the importance of seamless public health and hospital collaboration. NACCHO urges Congress to begin restoring funding to the Hospital Preparedness Program (HPP) by increasing it to \$300 million in FY2016. HPP is vital because this program provides grant funding to states and four directly funded cities to build healthcare coalitions that enhance regional and local hospital preparedness and improve overall surge capacity. The preparedness activities implemented under this program strengthen the capabilities of hospitals and other health care providers to respond to floods, hurricanes, or wildfires, and also include training for a potential influenza pandemic or terrorist attack. NACCHO also supports the \$110 million included in the President's FY2016 budget for a public health emergency response initiative at ASPR as a contingency fund to respond without delay to unforeseen emergencies.

NACCHO urges Congress to request information from ASPR on how state HPP funding is distributed, including how much is being allocated to local health departments and on what basis or formula each state allocates funds.

***Medical Reserve Corps - ASPR***

In 2002, the Medical Reserve Corps (MRC) was created after the terrorist attacks of 9/11 to establish a way for medical, public health, and other volunteers to address local health and preparedness needs. These highly skilled volunteers include doctors, dentists, nurses, pharmacists, and other community members. The program is comprised of 200,000 volunteers

enrolled in 1,000 units in all 50 states and territories. Two-thirds of MRC units are coordinated by local health departments. MRC volunteers provide an important community service, both filling gaps in routine health services and responding in emergency situations. NACCHO opposes the President's proposed cut to MRC and requests \$11 million in funding in FY2016 to restore the program's funding level to that of FY2014.

***Section 317 Immunization Program - CDC***

Immunizations continue to be one of the most cost-effective public health interventions. In an effort to prevent and control the spread of infectious diseases, the promotion of vaccinations is needed more now than ever, despite extraordinary public health successes. During the 2014 measles outbreak the United States experienced a record number of cases, with 644 cases from 27 states, according to CDC. From January 1 to March 27, 2015 alone, 178 people from 17 states and the District of Columbia were reported to have measles. The rapid spread of this disease illustrates the need for a strong public health immunization infrastructure to prevent disease in both children and adults. The 317 Immunization Program funds 50 states, six large cities and eight territories for vaccine purchase for at-need populations and immunization program operations, including support for implementing billing systems for immunization services at public health clinics to sustain high levels of vaccine coverage. In FY2016, NACCHO opposes the President's \$50 million cut and supports the \$8 million included in the President's budget to build health department capacity for billing to provide reimbursement for services.

***Foundational Capacities - CDC***

Foundational capacities is a new program to strengthen public health practice at state and local health departments and build core capacity in alignment with national accreditation standards.

As health care and public health agencies become more interconnected, it is essential that local health departments have the necessary capacity to engage in population health improvement in their communities. Therefore, NACCHO supports the President's request of \$8 million in FY2016 for the Foundational Capacities Program.

***Chronic Disease – CDC***

NACCHO appreciates efforts made by the Subcommittee to ensure that funding reaches the local level, where behavior and environments that prevent chronic disease are implemented.

NACCHO encourages continuation of this approach.

**Partnerships to Improve Community Health:** NACCHO urges the Subcommittee to provide \$80 million to support the continuation of the Partnerships to Improve Community Health program for FY2016. The program provides funding to 13 large cities/urban counties, 20 small cities/counties and 6 American Indian tribes/tribal organizations for the implementation of evidence-based strategies to address heart attacks, strokes, cancer, diabetes, and other chronic diseases that contribute to the increasing cost of health care. Grantees lead efforts to reduce tobacco use, increase physical activity and expand access to nutrition in order to reduce the prevalence of chronic diseases, such as heart disease and diabetes, through collaboration with community partners and businesses. These efforts complement the other CDC chronic disease programs listed below.

**Heart Disease and Stroke Prevention:** NACCHO urges the Subcommittee to continue to support Heart Disease and Stroke Prevention at \$130 million in FY2016. Heart disease is the leading cause of death for both men and women. The Heart Disease and Stroke Prevention program supports evidence-based programs in all 50 states and Washington, D.C. New funding

in FY2015 to 21 states and 4 cities requires states to fund local health departments to target at risk populations and promote healthy eating and exercise and reduce sodium intake, which can lead to high blood pressure and heart disease.

**Diabetes Prevention:** NACCHO urges the Subcommittee to continue support for Diabetes Prevention at \$150 million in FY2016. Diabetes is a chronic disease that affects more than 20 million people and can cause serious health complications including heart disease, blindness, kidney failure, and amputations. The CDC funds diabetes prevention and control activities in all 50 states and Washington, D.C. New funding in FY2015 to 21 states and four cities requires states to fund local health departments to target at risk populations and implement evidence-based approaches to support diabetes self-management education and lifestyle change.

***Prevention and Public Health Fund (HHS)***

In FY2016, NACCHO requests \$1 billion for the Prevention and Public Health Fund (PPHF), a dedicated federal investment in programs that prevent disease at the community level. PPHF supports the *Tips from Former Smokers* media campaign, efforts to reduce healthcare acquired infections and enhancing capacity in the public health workforce. NACCHO thanks Congress for allocating the PPHF in FY2015 and setting specific funding levels to support the prevention of disease and promotion of health in communities across the nation.

In conclusion, as the Subcommittee drafts the FY2016 Labor-HHS-Education Appropriations bill, NACCHO urges consideration of these recommendations for programs that protect the public's health and safety.

TESTIMONY OF

**Harry P. Selker, MD, MSPH**  
**Dean, Tufts Clinical and Translational Science Institute**  
**Executive Director, Institute for Clinical Research and Health Policy Studies**

ON BEHALF OF

**The Coalition for Clinical and Translational Science (CCTS), which includes**  
**Association for Clinical and Translational Science, 2025 M St NW, # 800, Washington, DC 20036;**  
**The Clinical Research Forum, 6701 Democracy Blvd, # 300, Bethesda, MD 20817;**  
**and other stakeholders**

REGARDING

**Fiscal Year 2016 (FY16) appropriations for clinical and translational research**  
**and research training and career development programs**  
**funded annually through the Labor, Health and Human Services,**  
**Education, and Related Agencies (L-HHS) Appropriations Bill**

SUBMITTED TO

**The House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services,**  
**Education, and Related Agencies**

ON

**The 23<sup>rd</sup> Day of April, 2015**

THE COALITION'S FY16 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH) to facilitate increased support for the full spectrum of medical research and also for research training and career development activities.**
  - **At least \$500 million for the Clinical and Translational Science Awards (CTSA) Program at NIH as part of a continued effort to provide the full funding level of \$750 million.**
  - **Implementation of the Institute of Medicines' CTSA Recommendations.**
  - **Proportional funding increases for additional clinical and translational research activities at NIH, including the Institutional Development Awards Program and the Research Centers at Minority Institutions Program.**
- **Provide a meaningful funding increase for the Agency for Healthcare Research and Quality (AHRQ) to facilitate increased support for research training and career development activities, and clinical research activities.**

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the clinical and translational research community as you work to craft the FY16 L-HHS Appropriations Bill. Before I begin, the community would like to thank you for your past support of the full spectrum of medical research.

#### ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and importance of federal clinical and translational research and research training and career development activities. The Coalition includes the Nation's leading health research institutions. CCTS's goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

#### **Association for Clinical and Translational Science (ACTS)**

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, state, and federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

#### **The Clinical Research Forum (CRF)**

CRF was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full

spectrum of research. Through its activities, the Forum has enabled sharing of best clinical practices and increasingly has played a national advocacy role in support of the broader interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, CRF is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

### SEQUESTRATION

Thank you for providing sequestration relief in FY 2014 and FY 2015.

Federal medical research programs form the cornerstone of our nation's biotech sector. In addition to undermining active and emerging research projects, across the board funding cuts create widespread disruption. Due to a number of factors, this disruption compounds significant challenges facing the clinical and translational research training and career development pipeline.

Recent years of near-level funding have curtailed NIH's ability to issue funding opportunities. As a result, the pay line at NIH has decreased substantially while the average age of an investigator receiving their first award has increased significantly. This dynamic creates a strong disincentive for young people to pursue a career in this field. Prior to sequestration, NIH would often discuss the decline in young investigators entering the research training and career development pipeline.

Beyond public health, our country needs to ensure that we are adequately preparing the next generation of medical investigators for reasons related to both the economy and national security. Recently, China announced a \$300 billion five-year investment in medical research; this amount is double the current NIH budget over the same period of time. With strong competition from foreign countries, we run the risk of a researcher brain-drain from the U.S. to other nations. Scientific breakthroughs and innovation will continue, but our loss in this area will mean gains for other nations. Foreign economies will benefit from the significant return-on-investment that occurs through robust support of research.

Sequestration has the potential to severely exacerbate an already difficult task of recruiting and training the next generation of scientific investigators. In order to ensure that the U.S. maintains



a strong research training and career development pipeline, please eliminate the threat of sequestration and further support key activities.

### NATIONAL INSTITUTES OF HEALTH

This nation has a proud history as a global leader in medical research and biotechnology. This leadership has provided our country with cutting-edge patient care, high-quality jobs, and meaningful economic growth. The Milliken Institute recently calculated that every dollar invested in NIH returns about a \$1.70 in economic output in the short term and as much as \$3.20 long-term. Crucially, through a robust external research program, NIH resources flow out to the states where the benefit of the funding infusion is felt on the local level.

NIH's impact on public health has been profound. Conditions once considered a death-sentence can now be managed, survival rates for patients with life-threatening diseases have increased dramatically, and additional innovative therapies and diagnostic tools come to market each year. NIH has been successful, but much more can be done. Please provide NIH with at least \$32 billion in FY16 so ongoing research projects can be adequately supported and new research activities can be initiated.

### **Clinical and Translational Science Awards (CTSAs)**

NIH's CTSA Program, which is housed within the National Center for Advancing Translational Sciences (NCATS), is transforming the efficiency and effectiveness of clinical and translational research. Since its establishment with 12 centers in 2006, the CTSA program has expanded to 62 of the leading medical research institutions located across the country. These centers are linked together and work in concert to improve human health by energizing the research and training environment to innovate and enhance the quality of clinical and translational research.

Recently, based on a recommendation by your Committee, the Institute of Medicine (IOM) released a review of the CTSA program. The report entitled, *The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research*, spoke favorably of the CTSA effort and made the following recommendations to improve the program:

(1) Strengthen NCATS leadership of the CTSA program, (2) reconfigure and streamline the CTSA Consortium, (3) build on the strengths of individual CTSAs across the spectrum of clinical and translational research, (4) formalize and standardize evaluation processes for individual CTSAs and the CTSA Program, (5) advance innovation in education and training programs, (6) ensure community engagement in all phases of research, (7) strengthen clinical and translational research relevant to child health.

CCTS supports the recommendations of the IOM report and the organization is hopeful these changes will continue to be implemented quickly. Another emerging opportunity is to promote collaboration between CTSAs and all NIH Institutes and Centers. Further, when the CTSA

program was authorized, Congress indicated that the consortium would be considered fully-funded when it received an annual appropriation of \$750 million. For FY16, as part of an overall funding increase for NIH, please provide CTSAs with at least \$500 million to ensure the program can continue to grow and advance. Additionally, we hope you will continue working over the coming years to provide CTSAs with \$750 million to fully fund the program and establish a robust home for clinical and translational research.

### **Institutional Development Awards Program (IDeA)**

The IDeA program broadens the geographic distribution of NIH funding for biomedical research. The program fosters health-related research and enhances the competitiveness of investigators at institutions located in states in which the aggregate success rate for applications to NIH has historically been low. The program also serves unique populations—such as rural and medically underserved communities—in these states. The IDeA program increases the competitiveness of investigators by supporting faculty development and research infrastructure enhancement at institutions in 23 states and Puerto Rico. Through Centers of Biomedical Research Excellence and IDeA Networks for Biomedical Research Excellence, the IDeA program builds important infrastructure and works to advance the field of clinical and translational research.

In FY16, please provide the IDeA program with a 5% increase to bring the total funding level up to around \$250 million. Such an increase would facilitate important growth in the program.

### **FEDERAL RESEARCH TRAINING AND CAREER DEVELOPMENT PROGRAMS**

As we discussed previously, the future of our nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. The "T" and "K" series awards at NIH and AHRQ provide much-needed support for the career development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K and T awards would have a devastating impact on our pool of highly trained clinical researchers. CCTS urges you to support the ongoing commitment to research training through adequate funding for T and K series awards and a meaningful FY16 funding increase for AHRQ.

Additionally, we are supportive of the overall effort being undertaken by the *21<sup>st</sup> Century Cures Initiative*, but we find some of the recommendations and the lack of funding authorizations within the current discussion draft to be worrisome. In future proposals, we hope to see additional funding authorized to support any and all new activities.

Thank you for the opportunity to present the views and recommendations of the clinical and translational research and research training and career development community.

TESTIMONY OF  
**Ken Singleton**  
**Executive Director**

ON BEHALF OF  
**The GBS/CIDP Foundation International (GCFI)**  
**104½ Forrest Avenue**  
**Narbeth, PA 19072**

REGARDING  
**Fiscal Year 2016 (FY16) appropriations for medical research  
and public health programs funded annually through the Labor,  
Health and Human Services, Education, and Related Agencies  
(L-HHS) Appropriations Bill**

SUBMITTED TO  
**The House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services,**  
**Education, and Related Agencies**

ON  
**The 23<sup>rd</sup> Day of April, 2015**

THE FOUNDATION'S FY16 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**
- **\$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY2016 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Allergy and Infectious Diseases (NIAID), and National Center for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions as you work to craft the FY16 L-HHS Appropriations Bill.

## ABOUT GBS, CIDP, VARIANTS AND RELATED CONDITIONS

### **Guillain-Barré Syndrome**

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis.

The cause of GBS is unknown. We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90% of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over six months to two years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

### **Chronic Inflammatory Demyelinating Polyneuropathy**

CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms.

It is the gradual onset as well as the *chronic* nature of CIDP that differentiates it from GBS. Fortunately, CIDP is even more rare than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1-2 in 100,000).

Like GBS, CIDP is caused by damage to the covering of the nerves, called *myelin*. It can start at any age and in both genders. Weakness occurs over two or more months.

Unlike GBS, CIDP is not self-limiting (with an end to the acute phase). Left untreated, 30% of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

### ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

### JIM'S STORY

I had GBS in 1973. This is important because the subject matter, IVIG treatments, were not available in 1973 and I believe that because it was not available, my experience with GBS was many times worse than it needed to be. I was totally paralyzed and only my head was able to move side to side. When the disease hit me, I was a college student in St. John's University in NYC in my fourth year and a newlywed of three months and I was also working thirty hours a week as a night manager in a busy Tire and Auto repair business. My wife and I were just beginning our lives together when GBS struck us down like a lightning bolt. My wife was also working full time and now the care of her totally paralyzed husband was in the hands of a nineteen year woman who was asked to do things and make decisions that no nineteen year old woman should have to make. I never finished college due to the amount of medical bills the accumulated and this affected my working life for decades. Keeping in mind the year, 1973, ICU care was very different then it is now. She was only allowed to visit me in the ICU for five minutes every hour. The rest of the time, she spent in a tiny waiting room with other ICU patient's families. She was at the hospital before work, at lunchtime and in the evening totaling about forty minutes a day. Imagine the stress on this young lady. I spent five weeks in the ICU, totally paralyzed with a tracheotomy and with no movement and no ability to communicate in anyway at all. Any need that I had had to be guessed by the four person nursing staff who also had a dozen other very ill patients who were in the open room that held all of these patients. Nights were a nightmare. They were long mostly because I was not sleeping well, day or night.

Minutes seemed like hours, and hours seemed like weeks. I was aware all of the time and it was like I was in a glass shell, unable to get out. The hospital staff tried, but no one could understand what it was like to be in that bed. One memorable evening, the tube that was connected to the MA-1 ventilator popped out of my neck and I was not getting any oxygen. Nobody saw that the bellows of the ventilator had dropped down. Someone had to see the situation or I was in big trouble. I had passed out from lack of air. Someone finally saw that it was not breathing for me. The "crash cart" finally got to me and I began to get some air. People started yelling "why didn't the alarm sound" There was an alarm that sounds if the machine failed for any reason. Two D cells powered the alarm and they were dead. Two D cells almost did me in.

I firmly believe that if IVIG was available for me in 1973, I would have never been so paralyzed and in need of a ventilator. My life was in the hands of a hospital staff and machinery and humans who make mistakes. Time and time again, IVIG has arrested the progress of GBS patients and prevented a patient from needing a vent and putting their life in danger. GBS in and of itself generally does not cause a patient to die, it is poor care or a late diagnosis or preexisting conditions. IVIG is a lifesaver and huge factor in reducing the level of paralysis and the amount of time that a patient is in hospital and rehab. I wish that IVIG was available when I had GBS. Its availability would have a huge difference in my case.

### SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into GBS, CIDP, and related disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was \$6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the

Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

CDC and NCCDPHP have resources that could be brought to bear to improve public awareness and recognition of CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities.

#### NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, variants and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. In fact, NINDS, NIAID, and the Office of Rare Diseases Research (ORDR) housed within NCATS have expressed interest in hosting a State-of-the-Science Conference on autoimmune peripheral neuropathies. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

Thank you for your time and your consideration of the community's requests.

TESTIMONY OF  
**Michael Weamer**  
**President and CEO**

ON BEHALF OF  
**The Marfan Foundation**  
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**Port Washington, NY 11050**

REGARDING  
**Fiscal Year 2016 (FY16) appropriations for medical research  
and public health programs funded annually through the Labor,  
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  - A proportional FY16 funding increase for CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD).
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).



Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the FY16 L-HHS Appropriations Bill.

## ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

### **Marfan Syndrome**

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

Connective tissue is made up of proteins. The protein that plays a role in Marfan syndrome is called fibrillin-1. Marfan syndrome is caused by a defect (or mutation) in the gene that tells the body how to make fibrillin-1. This mutation results in an increase in a protein called transforming growth factor beta, or TGF- $\beta$ . The increase in TGF- $\beta$  causes problems in connective tissues throughout the body, which in turn creates the features and medical problems associated with Marfan syndrome and some related disorders.

Because connective tissue is found throughout the body, Marfan syndrome can affect many different parts of the body, as well. Features of the disorder are most often found in the heart, blood vessels, bones, joints, and eyes. Some Marfan features – for example, aortic enlargement (expansion of the main blood vessel that carries blood away from the heart to the rest of the body) – can be life-threatening. The lungs, skin and nervous system may also be affected. Marfan syndrome does not affect intelligence.

### **Related Conditions**

There are disorders related to Marfan syndrome that can cause people to struggle with some of the same or similar physical problems. Some examples are Loeys-Dietz syndrome, Ehlers-Danlos syndrome, and Familial Thoracic Aortic Aneurysm and Dissection.

Disorders related to Marfan syndrome can also cut lives short, particularly when they go unchecked, and they can deeply affect the quality of life of the individuals and families who must cope with them. Just like people with Marfan syndrome, those affected by related disorders need early and accurate diagnosis to ensure they receive proper care and treatment.

Many of these disorders are genetic conditions that, like Marfan syndrome, cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a problem that requires medicine and regular monitoring to determine appropriate treatment. Other features that may overlap with Marfan syndrome include those involving the heart, bones, joints and eyes. Related connective tissue disorders include:

- Loeys-Dietz Syndrome
- Ehlers-Danlos Syndrome
- Familial Thoracic Aortic Aneurysm and Dissection
- Mass Phenotype
- Ectopia Lentis Syndrome
- Beals Syndrome

- Bicuspid Aortic Valve
- Stickler Syndrome
- Shprintzen-Goldberg Syndrome

### ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

- We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

### ONE FAMILY'S STORY

Hector Roman was 36 years old when he died on June 25, 2012, of an aortic dissection caused by Marfan syndrome. He was never diagnosed with Marfan syndrome – despite being treated by several medical specialists for myriad health issues – and he did not know he was a risk of a sudden early death. He was in pain for days and didn't rush to the hospital because he was frustrated with the lack of help he was getting with his health concerns. He had no idea this delay would be deadly. After a few days in pain, he went into shock and a friend call 911. He died three days later during his third surgery.

Now, his partner, Teresita Mompeller, of Phoenix, AZ, is raising their three boys -- Jovan, 5, Joel, 3, and Justus, 2 – alone. After Hector died, Teresita learned about Marfan syndrome. Most alarming to her was that affected people have a 50 percent chance of passing it to their offspring. She had her sons checked immediately. Joel and Justus have been diagnosed with Marfan syndrome and already have aortic enlargement. While their condition is the same as their dad; their prognosis is better. The boys can live a normal life span because they have the diagnosis and are being monitored. They can avoid a fatal situation because they *know*.

Teresita, who has a Facebook page called “Do You Know Marfan?” (and a parallel page in Spanish) recently wrote: “Thanks to the work of The Marfan Foundation, I know that my boys have a greater chance of living a long life. I know first-hand what it is to be a mother with many questions and concerns about a rare disorder that nobody seemed to know anything about. The Marfan Foundation has guided me through all of my concerns. They have given me all the support and information needed to advocate for my children [so they receive] proper treatment.

The Foundation has given me and thousands of other people, the peace of mind that they are working hard to better the lives of those affected.”

### SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into heritable connective tissue disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was \$6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation’s biomedical research enterprise.

### CENTERS FOR DISEASE CONTROL AND PREVENTION

People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children – including serious conditions like aortic enlargement. Others have fewer features when they are young and don’t develop aortic enlargement or other signs of Marfan syndrome until they are adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, can get worse over time.

This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications. The earlier some treatments are started, the better the outcomes are likely to be.

Knowing the signs of Marfan syndrome can save lives. Our community of experts estimates that nearly half the people who have Marfan syndrome don't know it. CDC and NCBDDD have critical programs that can help improve awareness and recognition of warning signs, which can save lives. Some of these programs include CDC's Million Hearts Campaign and NCBDDD's newborn screening activities.

Additionally, we support the establishment of a new sports screening program to fund awareness in high schools around the country and prevent Marfan syndrome-related thoracic aortic aneurysm and dissection, which claims the lives of young athletes across the country each year. A contemporary example of this need is Isaiah Austin, who was diagnosed with Marfan syndrome just five days before he was supposed to take part in the NBA Draft. Had it not been for the intense testing each potential draftee undergoes as part of the process, Isaiah may never have been diagnosed. He story might have ended by him collapsing on national television or years before while he was playing basketball in college. He is a prime example that more needs to be done. Meaningful funding increases will allow CDC to establish this new activity.

### NATIONAL INSTITUTES OF HEALTH

NIH has worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

### **NHLBI**

After four years of recruitment and three years of follow-up evaluations the results of the first-ever multicenter clinical trial for our patient population conducted by the National Heart, Lung and Blood Institute's Pediatric Heart Network (PHN), were released at the November 2014 meeting of the American Heart Association. Patients, age 6 months to 25 years, were randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root). The study found that there were no significant difference in the rate of aortic root dilatation between the two treatment groups over a 3-year period; in lay terms this means the study found another viable treatment for our patients. The Marfan Foundation thanks both NHLBI and NIAMS for their dedicated support and careful execution of this trial.

### **NEI**

Ectopia lentis, dislocation of the lens, occurs in up to 60 percent of patients with Marfan syndrome. The central positioning of the lens depends on the zonule of Zinn, a fibrous structure which has fibrillin-1 as a major component. NEI-supported investigators are studying the protein interactions of fibrillin-1 in health and disease in the zonule of Zinn to understand the disease mechanisms that cause ectopia lentis. It is hoped that this research will provide therapeutic insights to better treat this complication of Marfan syndrome.

### **NIAMS**

NIAMS continues to support the Consortium for Translational Research in Marfan Syndrome, which is investigating the disease process in MFS. These studies, building on previous advances, are aimed at identifying new biological targets for therapy, as well as predictive biomarkers of vascular and skeletal manifestations, which are the major causes of mortality and morbidity in MFS.

**ORDR**

The National Center for Advancing Translational Sciences houses ORDR and leads other important activities. In addition to the Rare Disease Clinical Research Consortia, translational treatment development programs hold promise for the heritable connective tissue disorders community.

TESTIMONY OF

**Dory Kranz**  
**Chief Executive Officer**

ON BEHALF OF

**The National Alopecia Areata Foundation**  
**65 Mitchell Boulevard, Suite 200-B**  
**San Rafael, California 94903**

REGARDING

**Fiscal Year 2016 (FY16) appropriations for medical research  
and public health programs funded annually through the Labor,  
Health and Human Services, Education, and Related Agencies  
(L-HHS) Appropriations Bill**

SUBMITTED TO

**The House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services,**  
**Education, and Related Agencies**

ON

**The 23<sup>rd</sup> Day of April, 2015**

THE ASSOCIATIONS'S FY16 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**
- **\$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY16 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Child Health and Human Development (NICHD), and the National Center for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the FY16 L-HHS Appropriations Bill.

### ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

### ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

### DEIDRE'S STORY

It has been 15 years since I first found the bald patch on my head that would completely change the course of my life. As a student at Florida State University during my junior year I found a perfectly round bald patch while blow-drying my very thick long hair – my pride and joy! Little did I know then the significant effect alopecia areata would have on my life.

I followed the typical patient profile for this disease. I started with one patch the size of a 50 cent piece, which later evolved into patches of varying sizes all over my head, and then to total loss of all scalp hair, which progressed to the most severe form of the disease: total loss of all body hair including my scalp, eyebrows, eyelashes, etc. Recently, my hair has inexplicably started to grow back in a very patchy and strange fashion on my head, while most of my body still remains hairless; a perfect example of the completely unpredictable course of this disease, which can cause significant emotional turmoil and distress for the sufferer.

As a professional woman, this disease has had a severe impact on my life. I have to present a confident image to the outside world. Living in constant fear of being discovered as a bald woman, being thought to be sick, bizarre, or worse has always been on the forefront of my mind. The exorbitant cost for treatments such as cortisone injections, extremely painful with questionable efficacy, has been an issue for me along with the expensive cranial prosthetics. Over the course of the years these have cost me thousands of dollars. If a lawyer like myself has financial difficulty when it comes to paying for treatments and prosthetics (which are not covered by insurance due to lack of CMS coverage benefits for those with Alopecia Areata), can you imagine the plight facing those patients that live on limited or fixed income?

The fact that there is so little known about the causes or possible treatments/cure for this disease only adds to the pain and suffering. This is a disease that alters the way you see yourself and the way the outside world treats you, and also causes significant and often debilitating emotional distress. The fact that there is little that can currently be done adds to that pain and suffering. Patients face a bleak outlook. For me, it has been a constant battle. I have not lived a single moment in the 5,475 days since that I have not looked in the mirror and wanted to scream or cry, not a single day that I haven't thought that I am damaged, abnormal, or ugly because of my hair loss, not a single day that I haven't worried about how a client, colleague, friend, or love-interest might see and judge me. Many will say to me that "it is only hair" or "at least it's not cancer." These comments only frustrate and upset me more. The feelings of being ostracized as an outcast can become deafening, even for a confident, intelligent professional. I shudder to think how others who don't possess my strength of character handle the stresses of this disease.

It is only with additional funding for research that we might hope to improve the lives of the millions in the US living with alopecia areata. Few have even heard of the disease. That fact alone creates additional stresses and difficulties for those of us with the disease, constantly having to explain what is "wrong" with us. Increased research into viable treatment options and a



potential cure could significantly impact millions of lives, from small children to adults, facing the constant battle that comes from a total loss of self image and confidence.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

### SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into alopecia areata, skin, and autoimmune disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration.

### NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation's TDP, have the potential to identify biomarkers and develop therapeutic targets. In fact, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough lead to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

One exciting emerging opportunity is the new Accelerating Medicines Partnership (AMP) that was recently announced by NIH. This effort is outcomes-oriented and based on a public private-partnership model. Industry, patient organizations, and researchers work together to conduct research with the goals of improving treatments and diagnostic tools. Rheumatoid arthritis is one of the diseases being examined in the first round of study, which should generate opportunities for alopecia areata due to the similarities between the conditions. Please support AMP and encourage NIH to expand activities in this area, particularly when there is research overlap between conditions

### ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). This is because many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the guise of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program.

Further, FDA should be encouraged to review all originally-nominated conditions in a timely manner so the PFDDI can continue to move forward.

Additionally, Congressman Jared Huffman (D-CA-2nd) is working with the community on introducing a bill that will allow for Medicaid to cover a significant portion of the cost of a cranial prostheses when a doctor deems it medically necessary. The disease can be incredibly debilitating not only physically and psychologically but financially as well. This bill is designed to help lessen the burden placed upon those effected by the disease. Please consider cosponsoring the bill when it is introduced.

Thank you for your time and your consideration of the community's requests.

TESTIMONY OF  
**Mr. Rino Aldrighetti**  
**President and CEO**

ON BEHALF OF  
**The Pulmonary Hypertension Association (PHA)**  
**801 Roeder Rd, Suite 1000**  
**Silver Spring, MD 20910**

REGARDING  
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and public health programs funded annually through the Labor,  
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THE ASSOCIATIONS'S FY16 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**
- **\$7 billion in discretionary budget authority for the Health Resources and Services Administration (HRSA).**
- **\$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC),** which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY16 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Child Health and Human Development (NICHD), and the National Center for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension community as you work to craft the FY16 L-HHS Appropriations Bill.

### ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of the heart has to pump against to push blood through the lungs; and a strain on the right side of the heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of the heart can become overworked, become very weak and may possibly fail. Because blood has difficulty getting through the lungs to pick up oxygen, blood oxygen level may be lower than normal. This can put a strain not only on the heart, but also decrease the amount of oxygen getting to the brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

### ABOUT THE ASSOCIATION

From simple beginnings – four women who met around a kitchen table in Florida in 1990 – the Pulmonary Hypertension Association has evolved into a community of well over 10,000 pulmonary hypertension patients, caregivers, family members and medical professionals.

As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: *We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension.*

### **Research**

PHA provides grants to promising researchers in the field of pulmonary hypertension. The program fosters new leaders in the field by supporting their interest in PH research and providing them with opportunities to work with mentors and learn new skills. Researchers supported by PHA are looking for new methods for early detection, new treatments to prevent the onset of PH and ultimately a cure for this terrible illness. To date, PHA has leveraged more than \$15 million in PH research funding through partnerships with the NIH and others.

### **Early Diagnosis Campaign**

It takes too long for pulmonary hypertension to be diagnosed. The median survival rate without treatment is approximately 2.8 years, making the need to obtain a rapid and accurate diagnosis urgent. Unfortunately, the median duration from symptom onset to a confirmed diagnosis by right heart catheterization is 1.1 years. We are reaching patients too late in the process. Almost three-fourths of patients have advanced PH by the time they are diagnosed, leading more costly treatments and poorer outcomes. For the most advanced cases of PH, a lung or heart-lung transplant may be the only treatment option. The goal of PHA's Early Diagnosis Campaign is to discover the disease sooner in the early stages. This will allow the start of a treatment regimen that can slow the progression of PH and secure a better life for the patient.

### **Center Accreditation**

The Pulmonary Hypertension Association's Scientific Leadership Council, 28 global leaders in the field of pulmonary hypertension, have spearheaded the PHA-Accredited PH Care Centers (PHCC) initiative. The goal of this initiative is to establish a program for accreditation of centers with special expertise in pulmonary hypertension (PH), particularly pulmonary arterial hypertension (PAH), to raise the overall quality of care and outcomes in patients with this life-threatening disease.

### ONE PATIENT'S STORY

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong began experiencing shortness of breath and dizziness. She was in Afghanistan at the time. Jessica was first diagnosed with dehydration. Then, as is the case with many PH patients, she was told she had asthma and was given an inhaler. Two months later, she fainted for no apparent reason. An echocardiogram revealed blood clots in her lungs and Jessica was medically evacuated to Germany and then to the U.S. Six months after her first symptoms, she was finally given a complete work up and diagnosed with pulmonary hypertension.

Jessica, she had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE) – a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as “more painful than I could ever imagine.” She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, has only completed about 3,000 surgeries. The procedure that saved Jessica's life was developed in her lifetime.

Jessica was terminated from Army employment and spent \$60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to retain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the coordinator of our Early Diagnosis Campaign.

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. However, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research

holds the promise of a better tomorrow.

### SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that the pulmonary hypertension research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. The Association has anecdotal accounts of the harms of sequestration and the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was \$6 billion (22.4 percent) less than it was in FY03.
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- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Association asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

### HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with a meaningful funding increase in FY16.

### CENTERS FOR DISEASE CONTROL AND PREVENTION

As a result of federal investment in medical research, there are now twelve FDA-approved treatments for PH. The effectiveness of these therapies, however, is dependent on how early a patient can receive an accurate diagnosis and begin treatment. Unfortunately, two-thirds of patients are not diagnosed until PH has reached a late stage. In addition to mitigating the impact of many treatments, late diagnosis puts PH patients in a position to face interventions like heart-lung transplantation and even death. CDC and NCCDPHP have the resources to complement

PHA's own *Sometimes its PH* Early Diagnosis Campaign. Improving public awareness and recognition of PH will not only save lives, it can save the federal healthcare system money. Please provide CDC with meaningful funding increases so the agency can expand its focus into increasingly important and cost-effective areas.

#### NATIONAL INSTITUTES OF HEALTH

NIH hosts a sizable PH research portfolio. Further, NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The twelve FDA-approved treatments, more than nearly every other rare disease, are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment.

#### **NCATS**

The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases.

#### **NHLBI**

The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which began in FY 2014, provides a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.

TESTIMONY OF  
**Mr. Robert J. Riggs**  
**Chief Executive Officer**

ON BEHALF OF  
**The Scleroderma Foundation (SF)**  
**300 Rosewood Drive, Suite 105**  
**Danvers, MA 01923**

REGARDING  
**Fiscal Year 2016 (FY16) appropriations for medical research  
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Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the FY16 L-HHS Appropriations Bill.



### ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called “progressive systemic sclerosis,” but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient’s particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

### ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

### **Support**

The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

- A nationwide network of 24 chapters and more than 150 support groups
- A toll-free helpline providing information and referrals to callers
- Educational materials, including a quarterly magazine called "Scleroderma Voice"
- Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

### **Education**

As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

### **Research**

The Scleroderma Foundation budgets at least \$1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fiduciary responsibility to donors very seriously, especially with regard to our research grant program.

### ONE FAMILY'S STORY

Cheyenne Cogswell is an eight-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and the family – together with their close circle of friends – continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

### SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that the scleroderma research portfolio can continue to

grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration for FY16 and moving forward.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of “winnable battles.” Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

#### NATIONAL INSTITUTES OF HEALTH

NIH has worked with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis and pulmonary fibrosis that occurs during a heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS, NHLBI AND NIDDK.

Emerging NIH initiatives like the Cures Acceleration Network and the Accelerating Medicines Partnership are creating meaningful opportunities to advance scleroderma research. Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

- NHLBI, which is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.
- NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL-31) in producing inflammation and fibrosis, or scarring in scleroderma.

#### ADDITIONAL MEDICAL RESEARCH ACTIVITIES

In recent years, scleroderma has been listed as a condition eligible for study through the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). Since FY05, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over \$10 million in scleroderma research funding as well as the initiation of meaningful research projects. Military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it. The scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is continues to be listed as a condition eligible for study through the PRMRP within the Committee Report accompanying the FY16 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community’s requests.

TESTIMONY OF

**Karen L. Ball**  
**President & CEO**

ON BEHALF OF

**The Sturge-Weber Foundation**  
**1240 Sussex Turnpike, Suite 1**  
**Randolph, NJ 07869**

REGARDING

**Fiscal Year 2016 (FY16) appropriations for medical research  
and public health programs funded annually through the Labor,  
Health and Human Services, Education, and Related Agencies  
(L-HHS) Appropriations Bill**

SUBMITTED TO

**The House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services,**  
**Education, and Related Agencies**

ON

**The 23<sup>rd</sup> Day of April, 2015**

THE FOUNDATION'S FY16 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**
- **\$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY2016 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and National Center for Birth Defects and Developmental Disabilities (NCBDDD).
- **At least \$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and the National Institute for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Sturge-Weber syndrome, Kippel Trenaunay, and Port Wine Birthmarks as you work to craft the FY16 L-HHS Appropriations Bill.

### ABOUT STURGE-WEBER SYNDROME AND RELATED CONDITIONS

Sturge-Weber syndrome (encephelotrigeminal angiomas) is a congenital, non-familial disorder of unknown incidence and cause. It is characterized by a congenital facial birthmark ("Port Wine Birthmark") and neurological abnormalities; neurological concerns relate to the development of excessive blood vessel growth on the surface of the brain (angiomas). These angiomas can cause life-long seizures, a weakening or loss of the use of one side of the body (hemiparesis), as well as delay the development of motor and cognitive skills.

### ABOUT THE FOUNDATION

The Sturge-Weber Foundation is a 501c3 incorporated in 1987 by individuals affected by Sturge-Weber syndrome, Kippel Trenaunay, and Port Wine Birthmarks. Our mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port Wine Birthmark conditions through collaborative education, advocacy, research and friendly support. The Foundation and our nationwide network of dedicated volunteers continuously work to advance research, raise awareness, and provide empowerment.

The Vision of the Sturge-Weber Foundation is that in all areas of life – public, professional, personal – these goals will be achievable for our members.

In Awareness – when the public will be able to see past the disability to the person.

In Empowerment – when families and individuals will be able to obtain the medical care, employment, education, respect and personal achievement they seek

In Research - when the pace of discovery will not be hampered by lack of resources and will lead continually toward a cure and advances in treatment.

### ONE PATIENT'S STORY

This is the first thing I've written in three years, except for graduate school papers and my thesis which don't really seem to count. It's not that I don't write. I just haven't had the courage to write since experiencing a psychotic break in 2011. This "break" was the culmination of clinical depression that was untreated because of insurance, an eye surgery to treat my glaucoma, three months of bed rest after my doctors took too much tissue out during the surgery, and the inability to see because the surgery was on my dominant eye. I've had great challenges in my life. I've been fighting for a quality life since I was born with Sturge-Weber Syndrome. My life long struggle to fight vision loss, depression, alienation from my peers in school, and the supposition I

would never have more function than a steamed vegetable has made me a fighter, but with every fighter there comes a breaking point. Mine just came the winter of 2011.

As an individual, and an advocate, with Sturge-Weber Syndrome I have fought with tenacity to provide hope for families and “patients” alike while providing education to doctors, news broadcasts, and even testify before Congress at age 13. Life isn’t all bad all the time. I’ve been like almost every college student in America. I went away, I lived with roommates, and I’ve gone out to bars. After graduating in 2009, I too experienced the struggle of not being able to find a job in my field. I’m one of the graduates still living at home and not working to my full potential. Where I differ from the other millennials like myself is I have medical bills, co-pays, and medicine to pay for on a monthly basis. There are perhaps very few 28 year olds in the world that have to figure out how to pay a \$2,000 deductible prior to receiving treatment for a port-wine stain which left untreated will lead to a more protruded and darker colored birthmark. Leaving it untreated would only further marginalize me. I have enough trouble finding a date as I am and there is no way I want to further allow myself to become a dog lady by not taking care of my health. Still the matter remains, how does one pay her 2,000 deductible for treatment when she only makes 25,000 before taxes?

There are days I have longed to be youthful and never worry about where the money for the next MRI will come from. I’d love to be one of those people that never need to go to the emergency room because of the migraines and ischemic strokes caused by the port-wine stain on my brain. I would SINCERELY love to have the non-functioning half of my brain back. Despite all the wishes, wants and dreams, I know I am blessed. Most people don’t get to meet Congressmen and Julianne Moore, or be told they are an inspiration of courage and bravery by a favorite band. Granted, it’s not winning the Betty Ford Award, like my mom when I was a baby, but through the years you learn to take each day with grace. That is until some six year old says “Eww! Mommy look at the pig!” That’s that time when grace is challenging, but what makes medical research funding and education SO important!

## SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into Sturge-Weber syndrome and related conditions can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was \$6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.

- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate \$300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

Recently, it was discovered that Sturge-Weber syndrome occurs due to somatic mutation (a genetic mutation that occurs after conception). In this regard, public health activities at the Centers for Birth Defects Research and Prevention (CBDRP) at the NCBDDD is incredibly important to our community. Specifically, the National Birth Defects Prevention Study (NBDPS) and the Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS) are important efforts that identify what causes birth defects and how to prevent them. NCBDDD and CDC as a whole need proportional and meaningful increases in their budget in order to continue the important work in this field.

#### NATIONAL INSTITUTES OF HEALTH

The Office of Rare Diseases Research (ORDR) housed at NCATS hosts a small research portfolio focused on Sturge-Weber syndrome and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. Such programs as the Brain Vascular Malformations Consortium (BVMC) within the Rare Diseases Clinical Research Network (RDCRN) are incredibly important because they fund Sturge-Weber syndrome specific research. However, these continued advancements can only be made with stable increases in the overall NIH budget.

Additionally, Sturge-Weber syndrome falls under NEI, NIMH, NCI, NHLBI, NIAMS and NINDS disciplines. In this regard, it is important to promote Sturge-Weber portfolios at these Institutes as cross-cutting information sharing is paramount in continuing the advancements in this field. In order to accomplish this goal increases in each institutions budgets are required.

Thank you for your time and your consideration of the community's request.

**Person Submitting Testimony:**

**Robert and Evelyn Greene**      e-mail; [rgreene4@mac.com](mailto:rgreene4@mac.com)  
**7570 E Speedway #332**      Home phone: 520-721-0254  
**Tucson, AZ 85710-8818**

**Testimony Prepared For:**

House Appropriations, Subcommittee on Commerce, Justice, Science and Related Agencies

**Regarding:**

U.S. Department of Justice (DOJ)

**Requesting:**

Conditions consistent with the *Olmstead* decision on federally-funded DOJ court actions that involve the residents of Medicaid-licensed Intermediate Care Facilities (ICFs/IID) or other specialized Medicaid-licensed facilities for persons with intellectual and developmental disabilities.

**Submitted by email:** [CJ.Approp@mail.house.gov](mailto:CJ.Approp@mail.house.gov)

We are writing to urge the Subcommittee to build on favorable Report Language passed last Congress relating to the Department of Justice's (DOJ's) deinstitutionalization actions pursuant to its enforcement of the Americans with Disabilities Act (ADA), as motivated by the U.S. Supreme Court's *Olmstead* decision.

This Report Language, passed by Congress, "strongly urged" DOJ "to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act."

This language does not go far enough. We are asking this Subcommittee **to support bill language that conditions DOJ appropriations - prior to bringing any court action that involve the residents of a Medicaid-licensed Intermediate Care Facility (ICF/IID) or other specialized Medicaid-licensed facility for persons with intellectual and developmental disabilities (I/DD) - on DOJ first consulting with residents, or their legal guardians, to determine residents' needs and choices with regard to residential services and supports and, consistent with the *Olmstead* decision, not impose community-based treatment on individuals who do not desire it.**

From 2009 to 2014, DOJ's Civil Rights Division was involved in more than 45 *Olmstead* actions in 25 states, most of which were aimed at moving individuals from specialized care and work settings ("deinstitutionalization") to smaller, "community-based" settings.

Rarely in these actions did DOJ factor in individual needs and choices, or family input, and some have resulted in tragedies. For example, in Virginia, Nebraska, Georgia, and Tennessee, high mortality rates have been reported in the wake of DOJ's deinstitutionalization settlement enforcement. Just last week, on March 21, the *Augusta Chronicle* reported that of the 499



individuals with profound I/DD who have been transferred from Medicaid-licensed facilities pursuant to a DOJ "Olmstead enforcement" settlement, 62 (12%) have died unexpectedly. Overall, there have been 1,000 deaths over two years (2013-2014) in community settings, 22% of which were "unexpected."

**Most tragic is that these deaths and other tragic outcomes (hospitalizations, abuse, neglect and injuries) were predictable. They've happened time and again in Georgia and other states.**

DOJ's actions, which force people with I/DD from specialized homes, are contrary to *Olmstead*. The Supreme Court's holding in *Olmstead* only requires community placement when such placement is not opposed by the individual. The Court also stated: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings....Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."

**Thank you for supporting bill language that conditions DOJ appropriations, prior to bringing any action, on DOJ first consulting with residents, or their legal guardians, to determine residents' needs and choices with regard to residential services and supports and, consistent with the *Olmstead* decision, not impose community-based treatment on individuals who do not desire it.**

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. **We support VOR's testimony.**

Our 53 year old daughter is profoundly mentally retarded and has been "institutionalized" for 50 of those years. She is a Rett's syndrome woman and requires full care 24/7. She has received excellent care for all these years and we are aware what de-institutionalization does to people with her disabilities – they generally do not receive the care required and suffer abuse and premature death in community homes. **Please play heed to our request and the request of VOR.**

Thank you,

Robert and Evelyn Greene

**Written Testimony of Megan Kennedy of Missouri  
Labor, Health and Human Services, Education, and Related Agencies  
Subcommittee of the House Committee on Appropriations  
April 24, 2015**

**30 year old woman with Usher syndrome, Founder of the Megan Foundation, Board member of the Usher Syndrome Coalition**

My name is Megan Kennedy and I'm from the state of Missouri. As Founder of The Megan Foundation, and a member of the Usher Syndrome Coalition's Board of Directors, I write on behalf of the Usher syndrome community to respectfully request this committee prioritize research into the causes of Usher syndrome and into treatment options at the National Institutes of Health (NIH).

As you prepare the Fiscal Year 2016 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language:

*The Committee commends NIH for including Usher syndrome on the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) list in order to track the annual support level of this rare disease. The Committee urges NIH to prioritize Usher syndrome research at the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI) and develop a multidisciplinary research strategy among multiple NIH institutes, including the National Center for Advancing Translational Sciences (NCATS), the National Human Genome Research Institute (NHGRI), and the National Institute of Mental Health (NIMH). Because Usher syndrome is a rare genetic condition, the Committee urges NCATS to support fundamental basic science research on Usher syndrome and NHGRI to support research on the underlying genetic causes of Usher syndrome. Since children and adults with Usher syndrome are at risk for the development of mental and behavioral disorders, the Committee urges NIMH to support research to elucidate genomic risk factors that underlie mental disorders. The Committee urges additional focus from NIDCD, given Usher syndrome's involvement with vestibular dysfunction. The Committee requests an update in the*

*fiscal year 2017 CJ on the planned and on-going activities related to this syndrome, including the manner in which various ICs coordinate on common goals and objectives.*

Usher syndrome is the most common cause of combined deafness and blindness. In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. I am one of these people. Born with a hearing impairment of approximately 80%, it wasn't until I was 22 years old that I learned I had Usher syndrome Type 2a, and that I was already considered legally blind. Today, at age 30, I have a field of vision of only 10 degrees.

Hearing aids are incredible tools that I have used since I was 3 years old, but they cannot perfectly mimic normal hearing. Biology has developed a sophisticated system of hearing between the cochlea and the brain. The cochlea, a sound-transmitting device within our ears, works so seamlessly with our brains in interpreting signals that it can actually distinguish which sounds to focus on, and which sounds to ignore as background noise. This system has the ability to hone in on a conversation with a friend in a loud restaurant, for example, while minimizing the distracting noises of clattering plates and nearby conversations. Think of it as auto-adjusting. Hearing aids, while having come a long way, do not have the capability to separate foreground noise from background noise as naturally as this biological system, making the brain work much harder to distinguish between the two.

I have never experienced the luxury of normal hearing. The machines in my ears interrupt the seamless flow of hearing between the cochlea and brain by delaying the transmission of vibrations to be interpreted. All of my life, being a fluid part of conversations has been a laborious task. Not only do I have to manually distinguish between foreground and background noises, I also have to give my undivided attention to the direction a conversation is heading, as my brain catches up to interpret the delayed signals from my hearing aids. By the end

of the day, I'm weary with fatigue as I take out my hearing aids to rest from my chaotic world of noises.

Normal vision is about 180 degrees in a peripheral field of vision. With only 10 degrees of vision, I see about 5% of what the rest of the world sees. When I open my eyes in the morning to look at my husband, I only see a small portion of his handsome face. I scan his facial features in sections: his eyes, his forehead, his mouth, his chin. Then I put together the pieces to make a picture of what he looks like in that moment. Sometimes it takes a minute before I realize his eyes are open, looking back at me, and he's greeting me with his beautiful smile.

I'm lucky that I'm still able to see the people and things I love, but soon even that will be gone. In the meantime, it is the constant scanning and putting together the pieces that make seeing an exhausting task to perform every day. Imagine a life where seeing is a draining action, rather than a liberating one. So many tasks in our daily lives become effortless with vision, such as reading the numbers on a measuring cup, walking up and down stairs, finding an app on the iPhone, or determining whether it's safe to cross the street. When vision is compromised, everything in life becomes compromised.

My vision loss is now to the point where my career has been compromised, and pursuing a life-long dream in architecture is no longer feasible. I deserve to have a long and satisfying career, and I deserve to enjoy the simple pleasures of life without an exorbitant amount of effort to do so. I aspire to be an active part of this society, because the society we live in is full of opportunities to create the life we choose to live. Usher syndrome, however, doesn't allow me to create the life I choose to live.

People with Usher syndrome share the same range of intelligence and work ethic as any other slice of America. Yet they suffer from an 82% unemployment rate. People with Usher

syndrome are born with the same emotional strength as any other American. Yet they have a suicide rate that is 2 ½ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated \$139 billion annually in direct and indirect costs for people with eye disorders and vision loss. That doesn't even include the costs associated with hearing impairment.

I have spoken with and have met hundreds of people who are determined, focused, and working everyday to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells, which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Through the Usher Syndrome Coalition, we have brought the Usher community and researchers together by:

- Establishing an international registry of individuals with Usher syndrome, available for research or clinical trials at no cost, with individuals from all 50 states and 44 countries.
- Sponsoring an international research symposium at Harvard Medical School in July 2014 to develop a roadmap for research to bring us closer to viable clinical treatments.
- Sponsoring annual family conferences and monthly conferences that provide information and support to all of those living with Usher syndrome.

With this in place, we are bridging the gap between families in need and researchers who are working tirelessly to find a cure. Researchers like those in Oregon and Pennsylvania who are working on gene therapy treatments, one of which began clinical trials in 2013. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher syndrome using a drug therapy that holds promise for rescuing vision as well. Researchers in Iowa, California,

Nebraska, Massachusetts, Florida, Texas, and many other states, who are collaborating with each other and with families through the Coalition to advance all kinds of Usher syndrome research.

But still this is not enough. Without Federal support, we cannot help any of the tens of thousands who have Usher, or countless others that will be born with this devastating genetic disorder in the future. There are dozens of different mutations that cause Usher syndrome, and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We are asking you to supply this last critical resource to help us find a cure.

Until very recently, there was no way of knowing how much money the National Institutes of Health (NIH) invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. Usher syndrome research still needs a lot more investment, but this is a great start.

We do not ask that the committee throw dollars at the problem. Only that they ensure the appropriate funding is available. The researchers are there, waiting to discover what now is just a dream. All we are asking for is a chance; a chance for deaf children and adults who are going blind, a chance to see. With your help, those with Usher syndrome, including myself, can once again dare to dream.

**Deters, Allison**

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**From:** Ross, Susan  
**Sent:** Friday, May 01, 2015 7:09 PM  
**To:** Cole, Tom  
**Cc:** Murphy, Sean; Bowie, Maria; Deters, Allison  
**Subject:** Fwd: Southern Oklahoma Resource Center closure action

Mr Chairman, I received the below email from a constituent of yours and I wanted to forward it to you. I expect the group VOR is mounting a grassroots campaign and more of these sort of letters will start flowing in.

This issue relates to the language Mr Womack requested regarding prohibiting protection and advocacy funds from being used to go to court and force deinstitutionalization and closure of institutions for the developmentally disabled.

We had discussed remaining silent on the issue and perhaps you having a conversation with Womack at some point about whether he would want to offer an amendment, or to get more of the story from his perspective, since carrying this language will be controversial within the disability community.

Just wanted you to see it, esp since it references your friend Jim Nicholson and he may have another perspective also.

Begin forwarded message:

**From:** Mary Paulsen <[paulsensew@att.net](mailto:paulsensew@att.net)>  
**Date:** May 1, 2015 at 6:38:01 PM EDT  
**To:** Susan Ross <[Susan.Ross@mail.house.gov](mailto:Susan.Ross@mail.house.gov)>  
**Subject:** Southern Oklahoma Resource Center closure action

Dear Ms. Ross,

My son is developmentally disabled and was recently forced to transfer to a community setting. I am happy that he is close to my home; but the conditions of the home where he was placed was Horrible! One of his roommates refused to wear clothes and went to the bathroom wherever he was in the house. The smell of the house was terrible! The community provider never placed enough staff in this house. The direct care did the best they could; but that did not prevent the many bathroom accidents.

This home with 3 severely developmentally disabled had no choice. The home was finally closed by Governor Mary Fallon. However there are so few private providers that placement in a better home took almost 5 months. Two Centers were closed at the same time; Southern Oklahoma Resource Center and Northern Oklahoma Resource Center. The other factor was that Jim Nicholson, Oklahoma's DDSD administrator at that time repeatedly said, "you need to put these individuals in the community; so they could be like the rest of the population". It sounded like these severely disabled individuals would become normal once they were placed in the community.

Many of these individuals did not have the ability, nor skills to work in the community. So they could not find jobs in the community meaning they sat in a house all day long with nothing to do.

Much of the pressure to place these severely disabled into the community comes from the Federal Government. We hope the Sub-committee will add language to the HHS appropriations bill prohibiting the use of Federal Funds that support FORCED de-institutionalization. Individuals who are severely disabled and their families deserve the right to choose where to live and receive services that meet their needs. Our Parent's group found, through research, that the cost was the same.

Mary Ann Paulsen, Mother and Co-guardian of a developmentally son.  
2312 Whispering Pine Blvd.  
Shawnee, Ok (405) 275-5275  
[paulsensew@att.net](mailto:paulsensew@att.net)

Recently lived at Ada, Oklahoma



**Written Testimony of Lanya McKittrick of Washington  
Prepared for the Labor, Health and Human Services, Education and Related Agencies  
Subcommittee of the House Committee on Appropriations  
April 24, 2015**

**Parent of a 15 and 7 year old sons with Usher syndrome, Parent Advocate representing the Usher Syndrome Coalition and individuals with Usher syndrome, Founder of the Hear See Hope Foundation.**

My name is Lanya McKittrick and I'm from the state of Washington. I am here on behalf of the Usher Syndrome Coalition and the Hear See Hope Foundation to respectfully ask this committee to encourage the National Institutes of Health (NIH) to prioritize research that will expand treatment options for those who experience hearing, balance and vision problems due to Usher syndrome.

As you prepare the Fiscal Year 2016 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language:

*The Committee commends NIH for including Usher syndrome on the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) list in order to track the annual support level of this rare disease. The Committee urges NIH to prioritize Usher syndrome research at the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI) and develop a multidisciplinary research strategy among multiple NIH institutes, including the National Center for Advancing Translational Sciences (NCATS), the National Human Genome Research Institute (NHGRI), and the National Institute of Mental Health (NIMH). Because Usher syndrome is a rare genetic condition, the Committee urges NCATS to support fundamental basic science research on Usher syndrome and NHGRI to support research on the underlying genetic causes of Usher syndrome. Since children and adults with Usher syndrome are at risk for the development of mental and behavioral disorders,*

*the Committee urges NIMH to support research to elucidate genomic risk factors that underlie mental disorders. The Committee urges additional focus from NIDCD, given Usher syndrome's involvement with vestibular dysfunction. The Committee requests an update in the fiscal year 2017 CJ on the planned and on-going activities related to this syndrome, including the manner in which various ICs coordinate on common goals and objectives.*

Usher syndrome is the most common cause of combined deafness and blindness. In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. Even more people have retinitis pigmentosa (RP), which causes the retinal degeneration associated with Usher syndrome.

Conner was diagnosed with a profound hearing loss just after birth. He received his first cochlear implant when he was 1 year of age. He spent years of intense speech therapy to be mainstreamed into a regular Kindergarten class. At the age of 6, just after he started being mainstreamed, he began to be afraid of the dark. We took him to a routine eye exam only to have our worst nightmare come true. Our son would lose his vision before he becomes a young adult. Soon after Conner's diagnosis we found out that our newborn son, Dalton, also has Usher syndrome. We were devastated that two of our four boys would not only be deaf but lose their vision as well.

Conner and Dalton try to remain positive, but they cannot do many of the things their friends and family can. Conner has dreams to be an oceanographer. I hope those dreams can come true. I worry every day about his ability to succeed at a job if he is legally blind. The unemployment rates for those with Usher syndrome is very high and that is scary. Conner's

friends are driving but he'll never drive. Conner is excluded at many social events because he misses many of the gestures his friends make and has a hard time seeing details around him.

In 2004, my husband and I started the Hear See Hope Foundation to raise money for Usher syndrome research. We've funded over 1 million in research so far. But we can't find a cure without more funding. For the first time since my boys were diagnosed, I've felt comfortable telling them there is hope for treatment. But, we need more funding for research that will lead to clinical trials. For our family, we know that Conner has lost a lot of eyesight but our goal is to not have to see our younger son go through the difficult times that we see Conner go through.

Without more funding, both my boys will be legally blind within 10 years and that is heartbreaking.

There is brilliant research already being done including the first ever human clinical gene therapy trial at the Casey Eye Institute in Oregon. Other great research is being done by many other researchers and institutions as well.

Until very recently, there was no way of knowing how much money the NIH invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. Usher syndrome research still needs a lot more investment, but this is a great start.

Rare diseases with similar incident rates average around \$50 million annually. These investments have resulted in significant discoveries for these diseases, and I believe we can see

the same results or better for Usher syndrome. We dream for the opportunity for our kids to see their children and to fulfill all their dreams.

Thank you on behalf of all those with Usher syndrome, their families and our family.

Please let me know if you have any questions.

**WRITTEN TESTIMONY FOR THE RECORD**  
**OF RICHARD E. WARSINSKEY, PRESIDENT**  
**NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS**  
**Submitted to the House Committee on Appropriations**  
**Subcommittee on Labor, Health and Human Services,**  
**Education, and Related Agencies**  
**Regarding the Social Security Administration's FY 2016 Appropriation**  
**April 24, 2015**

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration's (SSA's) Fiscal Year (FY) 2016 Appropriation. NCSSMA respectfully requests that Congress consider full funding of the President's FY 2016 budget request, which includes \$12.513 billion for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will allow SSA to improve and modernize customer service, enhance program integrity efforts, deter and detect fraud and errors, and continue to address high volumes of work.

NCSSMA is a membership organization of 3,200 SSA managers and supervisors who provide leadership in 1,250 community-based field offices and teleservice centers throughout the country. Since our founding over forty-five years ago, NCSSMA has considered a stable SSA, which delivers quality and timely community-based service to

the American public, our top priority. We also consider it paramount to be good stewards of the taxpayers' monies and the programs we administer.

NCSSMA appreciates SSA's FY 2015 LAE account funding of \$11.806 billion.

Increased resources, particularly in field offices and teleservice centers, have a positive impact on delivering vital services to the American public and in fulfilling stewardship responsibilities. As indicated in the chart below, SSA field offices decreased by 3,452 employees and teleservice centers lost 931 employees between FY 2010 and FY 2013. The FY 2014 hiring and the FY 2015 replacements for staff attrition are needed to help recover from several years of staffing reductions. Adequate and sustained funding is needed to maintain staffing levels and to ensure new employees receive the training necessary to become fully productive, which takes three years.

<b>SSA Staff Attrition</b> <b>End of FY 2010 - End of FY 2014</b>					
Component	FY 2010	FY 2013	FY 2014	Net Staff Difference*	Percent of Staff Losses*
All SSA	70,202	62,199	65,102	-5,100	-7.26%
Field Offices	31,331	27,879	29,682	-1,649	-5.26%
TSCs	5,206	4,275	4,535	-671	-12.90%
ODAR	10,055	9,510	9,266	-789	-7.85%
PSCs	11,868	9,957	10,674	-1,194	-10.10%
*Net Staff Difference and Percent of Staff Losses are from End of FY 10 to End of FY 14					

The dramatic growth in SSA workloads, along with the attrition in our offices, has emphasized how imperative it is that the necessary resources are received to maintain service levels vital to the nearly 65 million beneficiaries and recipients.

Despite agency strategic planning, expansion of online services, significant productivity gains, and the best efforts of management and employees, SSA still faces many challenges providing the service the American public has earned and deserves.

As a result of the significant staffing losses, SSA experienced a marked deterioration in services from FY 2012 through FY 2014. The scope of the deterioration in services is illustrated in the examples provided below.

#### Availability of an Appointment with a Field Office

- Beginning of FY 2012: 74% could get an appointment within 2 weeks. Less than 1% waited over a month for an appointment.
- End of FY 2014: 28% could get an appointment within 2 weeks. 47% waited over a month.

#### Waiting Times in Field Offices

- FY 2012: 18.8 minutes; and 4.8% or 2.15 million customers waited over an hour.
- FY 2014: 28.2 minutes and 13.3% or 5.42 million customers waited over an hour.

#### Field Office Telephone Service (Earliest data available FY 2012)

- FY 2012: Busy Rate: 7.4%; Answer Rate: 82.9%\*
- FY 2014: Busy Rate: 20.1%; Answer Rate: 67.3%\*

\* Note - Answer rate is 100% minus the busy rate and rate of caller hang up.

#### 800 Number Telephone Service

- FY 2012: Busy Rate: 4.6%; Hold Time: 4.2 minutes; Answer Rate: unavailable

- FY 2014: Busy Rate: 13.5%; Hold Time: 22.0 minutes; Answer Rate: 53.8%

With the improved appropriations and new staff brought on in FY 2014 and FY 2015, SSA is beginning to see substantive progress in addressing service deteriorations. To maintain this progress, we fully support the President's budget request of \$12.513 billion for SSA's LAE account in FY 2016. While this would be an increase of \$707 million over the FY 2015 level of funding, it is important to note that this includes inflationary increases of \$355 million in fixed costs. NCSSMA respectfully requests that Congress consider full funding of the President's budget request for SSA to maintain staffing in SSA's front-line components, cover inflationary increases, continue efforts to reduce disability backlogs, increase deficit-reducing program integrity work, and to address the significantly increased hearings backlog, currently at an all-time high.

The President's FY 2016 budget request includes \$1.439 billion dedicated to processing program integrity workloads, which is consistent with the Budget Control Act of 2011. Program integrity initiatives save taxpayer dollars and contribute to reducing the federal budget and deficit. The President's FY 2016 SSA budget request includes funds for the two most cost-effective tools to reduce improper payments—**medical continuing disability reviews (CDRs) and SSI redeterminations.**

*In FY 2015 SSA projections indicate the agency will complete 790,000 medical CDRs, which is an increase of 50%, and 2.255 million SSI redeterminations. The FY 2016 budget request calls for SSA to process 908,000 medical CDRs and 2.622 million*



**SSI redeterminations.** To process this large increase of medical CDRs and SSI redeterminations, the field offices and disability determination services (DDS) will need to maintain adequate staffing levels or there could be delays in processing initial disability claims and reconsiderations and degradation of services.

Again, SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. With the current fiscal challenges confronting SSA, we encourage Congress to consider changes to the Social Security and SSI programs that have the potential to increase administrative efficiency and lower operational costs.

We realize the FY 2016 funding level of \$12.513 billion for SSA's LAE account requested is significant in this difficult budget environment. However, Social Security serves as the most vital component of the social safety net of America and is facing unprecedented challenges. The American public expects and deserves SSA's assistance. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve and will be unable to process program integrity workloads, which save taxpayer dollars and reduce the federal budget and deficit.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the necessary service they deserve from the Social Security Administration.

**Friends of the Health Resources and Services Administration**

c/o American Public Health Association • 800 I Street NW • Washington, DC, 20001 • 202-777-2513

Nicole Burda, Deputy Director of Government Relations, American Public Health Association  
Testimony submitted for the record on April 24, 2015  
House Committee on Appropriations Subcommittee on Labor, Health and Human Services, and  
Education and Related Agencies

Friends of HRSA is a nonpartisan coalition of 170 national organizations representing millions of public health and health care professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health and achieve health equity. For fiscal year 2016, we recommend restoring HRSA's discretionary budget authority to the FY 2010 level of \$7.48 billion. Funding for HRSA is too low to address the nation's current health needs, let alone keep pace with the growing health demands. Since FY 2010, HRSA's discretionary budget authority has been cut by 18 percent and we are concerned that if the proposed House Labor-HHS allocation is adopted, it will be nearly impossible to adequately fund the important public health programs at HRSA.

Research has shown that access to high-quality primary care improves health and reduces costs. As we experience a growing, aging and more diverse population, alongside health professionals nearing retirement age, and an increase in health coverage nationally, it is ever more critical to make investments that improve access and support a high-performing workforce capable of meeting these changes and the expected increases in health care demands. Not only are there current and projected shortages in the health professional workforce nationwide, many urban and rural communities experience persistent shortages and lack access to care due to a geographic maldistribution of providers. Restoring funding to HRSA will allow the agency to more effectively fill the preventive and primary care gaps for people living in areas where the need has been demonstrated and is reflected by suboptimal health outcomes.

HRSA operates programs in every state and U.S. territory and is a national leader in improving the health of Americans by supporting a workforce of sufficient size and skill, and providing high-quality health services. HRSA programs work synergistically and in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to create a complete mechanism to provide primary care providers for health centers and other direct providers of health care services for underserved areas and populations. AHECs serve as an integral part of the mechanism that recruits providers into primary health careers, diversifies the workforce and develops a passion for service to the underserved in these future providers.

In addition to internal coordination, HRSA is increasing coordination across the federal government to enhance the collective impact of improved health outcomes. Through maternal and child health programs, HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health. HRSA programs have helped reduce AIDS-related deaths through providing drug treatment regimens for people living with HIV and have the potential to prevent the spread of HIV by 96 percent. The Title X Family Planning Program, the only federal grant program dedicated to providing people with comprehensive family planning and related preventive health services, has greatly contributed to decreasing unintended pregnancy – helping to prevent an estimated 870,000 unintended pregnancies in 2013.

Now is the time to make a strong investment in a robust workforce and to improve access to care to continue achieving the health improvements HRSA has made and to pave the way for new achievements. The nation only stands to benefit from a healthier population which can translate into a stronger and better functioning nation, a thriving and productive workforce, and

reduced health care costs. Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs, including:

- Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so that health professionals are well-equipped to care for the nation's changing demographics.
- Primary care programs support more than 9,000 health center sites in every state and territory, improving access to preventive and primary care for more than 21 million patients in geographically isolated and economically distressed communities. Health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services – often delivering the range of services in one location. Close to half of all health centers serve rural populations. In addition, health centers target populations with special needs, including agricultural workers, homeless individuals and families and those living in public housing. As health insurance expands, health centers and other programs administered by HRSA will continue to play a critical role in the health care system serving as vital source of care for newly insured patients, and remaining an important source of care for those who cannot gain access to coverage.
- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health,

reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for 42 million women and children. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that a community-based system of family centered services is available for coordinated long-term follow up for babies with a positive screen and for all children with special health care needs such as children with autism and other developmental disabilities.

- HIV/AIDS programs provide the largest source of federal discretionary funding assistance to states and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for about half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
- Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for over 4.5 million women, men and adolescents. Health care services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. Title X service sites provide the only continuing source of health care and education for four out of ten women, and six out of ten women consider it their main source of care.

- Rural health programs improve access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of health care services. The Office of Rural Health Policy serves as the nation's primary voice for programs and research on rural health issues. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas. In addition to improving the health of rural residents, a recent analysis completed in 2013 showed that for every dollar HRSA invested, about \$1.63 in additional revenue was generated in the community – the cumulative impact added up to \$19.4 million in new local economic activity over a three-year project period of an original investment of \$11.9 million.
- Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the nation's primary defense against injury and death from poisoning for over 50 years. For every dollar spent on the poison center system, \$13.39 is saved in medical costs and lost productivity, totaling more than \$1.8 billion every year in savings.

We urge you to consider HRSA's central role in strengthening the nation's health and advise you to adopt our FY 2016 request of \$7.48 billion for HRSA's discretionary budget authority.

Thank you for the opportunity to submit our recommendation to the subcommittee.

**STATEMENT BY WOMEN'S HEART ALLIANCE  
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**FY 2016 LABOR-HHS-EDUCATION APPROPRIATIONS: NIH, CDC, HRSA**

Women's heart disease is the number one killer of women in the United States. While awareness of this epidemic has increased, women's heart disease continues to be under-researched, go untreated and be misdiagnosed. Not enough is being done to recognize the differences and appropriately treat heart disease in women, and there are far too many women's deaths that can be prevented.

Cardiovascular disease (CVD) causes nearly 86 million women and men to suffer in the U.S., and it is projected that nearly 44% of adults in the U.S. will be living with CVD (costing the U.S. more than \$1 trillion annually) by the year 2030. The epidemic is only expected to get worse, yet research, treatment and prevention continue to go underfunded for cardiovascular diseases vis-a-vis spending on other diseases that have less impact on the numbers of lives affected and the costs of care. Direct medical costs from CVD are projected to rise to more than \$818 billion, and the cost of America's loss of productivity is expected to be over \$275 billion. We cannot afford the loss of life nor the adverse impact on our economy that will result if we do not do enough now.

The Women's Heart Alliance requests that Congress appropriate sustained funding for CVD research, prevention and treatment. While we understand the difficulty that Congress faces with reducing the budget deficit, we believe sequestration is not the solution.

#### **RECOMMENDATIONS FOR FUNDING:**

An FY 2016 appropriation of the following program funding levels will help advance the fight against heart disease, stroke and other cardiovascular diseases—the number one killer of women. Our recommendations for stable investments in heart health are fiscally and ethically responsible.

#### **Capitalize on Investment for the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute (NHLBI)**

WHA supports \$3.3 billion for NHLBI (a 10% increase) to sustain current activities and new investments in promising and critically needed scientific opportunities that will aggressively advance the fight against heart disease. Unfortunately, NHLBI extramural heart research has fallen 17% in constant dollar since 2002. Despite heart disease, stroke and other forms of cardiovascular disease being our Nation's No. 1 and most costly killer, NIH still invests only 4% on heart research and a mere 1% on stroke research. In addition to discovering improved prevention and treatment efforts, NIH-supported research supports jobs and advances economic growth and innovation. Adequate funding for NHLBI will lead to major advances in CVD research and treatment.



**Funding for the Centers for Disease Control and Prevention (CDC)**

WHA requests a total of \$155.207 million, the same as the President's FY16 request, for CDC's Heart Disease and Stroke total investments.

WHA requests for \$130.037 million that will allow the CDC's Division for Heart Disease and Stroke Prevention to sustain its participation in both the State Public Health Action and the complimentary State and Local Public Health Actions to Prevent Obesity, Diabetes, and Heart Disease and Stroke. It will maintain support for an evolving cardiovascular disease surveillance system, and research and evaluation.

WHA also asks the Committee to support the President's request for \$4 million to augment the Prevention and Public Health Fund for Million Hearts, a public-private initiative to prevent 1 million heart attacks and strokes by 2017. This would allow Million Hearts to enhance efforts to prevent, detect, treat, and control blood pressure—a key reason for heart attack and stroke.

Finally, WHA advocates for \$21.170 million to CDC's WISEWOMAN program to support the President's request. Well-Integrated Screening and Evaluation for WOMmen Across the Nation (WISEWOMEN) helps uninsured and under-insured low-income women ages 40 to 64 avoid heart disease and stroke. Of the nearly 150,000 women served by this initiative from July 2008 through June 2013, 90% of them had at least one heart disease and stroke risk factor. More than 100,000 of these women participated in at least one behavioral modification session.

**CONCLUSION**

Cardiovascular disease and its precursors are an unnecessary and heavy burden on America's people and budget. Investment in health research through NIH and CDC saves lives, improves quality of life and reduces health care costs in the long-term. We respectfully ask the Committee to approve these recommendations that will foster the health and well-being of the American people.



**Testimony Prepared by Sue Daugherty, RD, LDN - CEO, Metropolitan Area  
Neighborhood Nutrition Alliance (MANNA) for the United State House Committee on  
Labor, Health and Human Services, and Education, and Related Agencies addressed to the  
Department of Health and Human Services**

**Monday, May 04, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

MANNA is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 750,000 medically tailored, home delivered meals annually. Nearly 15,000 people have benefited from the 11 million meals that MANNA has delivered over our 25 year history. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has

identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support

services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. MANNA spearheaded a groundbreaking study comparing participants in our comprehensive medically-tailored FNS program vs. a control group within a local managed care organization. This study found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients'

costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

### **Conclusion**

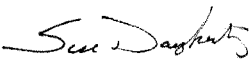
We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return

in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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**Person Submitting Testimony: Jeffrey L. Strully, Executive Director & Parent**

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies, including Administration on Intellectual and Developmental Disabilities (AIDD), National Council on Disability (NCD), and Centers for Medicare & Medicaid Services (CMS)

**Submitted by email: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)** (Subject Line: FY 2016 written testimony for the record)

Centers for Medicare and Medicaid (CMS), Administration on Intellectual and Developmental Disabilities (AIDD) and the National Council on Disability (NCD) have taken a bold and appropriate position by advancing the inclusion of all people with developmental disabilities including those that remain in segregated residential and day programs into the community.

VOR has once again raised its objections to all of the evidenced based practices as well as personal stories that exist in the field today by using choice as a way to keep things the same. While I understand that parents and siblings want to do the best that they can and they believe that the old models make the most sense for their adult children, we know that inclusion alongside non-disabled peers in the community is the way to go. The outcomes are very clear and while parents of institutionalized people do care for their “adult children” they are not making the best decision for their children but for themselves.

As a parent of three adult children who have developmental disabilities, I have personally seen their growth and development by living a life of inclusion, having meaningful employment opportunities, having relationships with and without people with disabilities, having a life that is based on their individual hopes and dreams does matter. I have seen growth in all areas of activities of daily living and independence.

In addition to being a parent, I have been the Executive Director of Jay Nolan Community Services for the past twenty-three years. JNCS provides services to over 440 people with autism and other developmental disabilities in Los Angeles and the surrounding area as well as in San Jose, California. JNCS is one of a number of organizations that have converted from traditional services (group living, group day services, site based programs) to an individual and personal approach. As a result of these changes, we have seen the following outcomes:

- a) The use of psychotropic medication has been reduced
- b) Staff turn-over has been reduced
- c) Special Incidents Reports have been reduced
- d) Property destruction has been significantly reduced
- e) Aggression has been reduced and that which remains has been diminished in its intensity, duration and frequency
- f) There has been increased choice and control by people with disabilities
- g) There are many other positive outcomes that have been achieved using the limited resources that exist in this sector.

**Concluding Statement**

Tying funding with evidenced based practices and good overall policy such as what these agencies have produced not only makes sense, but is the logical way to proceed. I am sorry that a small group of well-meaning people continue to try and perpetuate a model of services that has come and gone. The big institution has had its day in history. Now is the time to move to individualization, personalization and customization of services but working for much higher returns on our investment. It is time to actively support the proposed changes that are taking place in Washington and wanting to see outcomes that demonstrate how our national resources are producing results that we are all proud of and wanting to enhance.



**Testimony Prepared by Paul Getzel, Director of Chicken Soup Brigade, Lifelong's Food Program, for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Lifelong is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 162,000 million medically tailored, home delivered meals and 40,000 bags of healthy groceries annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase

absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

## **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a

control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

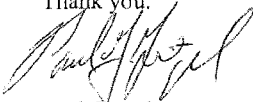
## Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you,



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**Testimony of  
David Lujan, Executive Director of Public Policy  
Reading Partners  
Before the House Labor, Health and Human Services, Education and Related Agencies  
Appropriations Subcommittee  
House Committee on Appropriations  
April 29, 2015**

Mr. Chairman, members of the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee, thank you for the opportunity to submit this statement to you. I am David Lujan, the Executive Director of Public Policy for Reading Partners, a national education nonprofit that works with Title I elementary schools to support students who are reading below grade-level. On behalf of Reading Partners, I urge you to combine the **Striving Readers** and the **Innovative Approaches to Literacy** programs at the Department of Education and to provide the combined program \$185 million for Fiscal Year 2016. This is the level funding from the Fiscal Year 2015 budget. In addition, I recommend some programmatic changes which will strengthen the new program and make it more effective. Those changes are discussed below.

But first, I want to emphasize the need for such programs. As you all know, literacy is a staggering problem in this country. It is estimated that over 9 million students read below grade level. Four out of five fourth graders from low income families cannot read at grade level. The consequences of these numbers are deeply troubling. Children that cannot read proficiently by the fourth grade are four times more likely to drop out or graduate late.

Yet, despite the magnitude of the problem, the federal government has not devoted the resources I believe it must, to provide solutions. Spending \$185 million for designated literacy programs will simply not get the job done. The federal government spends \$3.4 billion each year on STEM education through a number of agencies. I am not arguing to spend less on STEM, but

I am saying that our literacy needs are just as urgent. Spending on literacy should be greatly increased. In point of fact, reading is an integral part of STEM comprehension.

As a realist, I realize that getting more money dedicated to literacy in Fiscal Year 2016 is unlikely. We are working with the House and Senate authorizing committees with jurisdiction over the Elementary and Secondary Education Act to see that the next version of the bill has a more robust literacy program.

Given the limited amount of funding -- \$185 million -- it is essential that the money be spent as wisely as possible. For that reason I am recommending that a number of changes be made. Striving Readers is a program created by this committee. As such I am hoping that you will amend it.

First, I recommend that the program be re-competed at once and again every three years. It is important for every State to get involved and have the potential for participation in federal funding. Second, the funds should not be used by State Departments of Education for planning. Instead the money should be put out into on-the-ground projects that deliver actual service to students. I recommend that a minimum of 90% of the money must go out in subgrants. Finally, States must subgrant the money to proposals backed by the strongest available evidence of effectiveness. Literacy programs have been in existence for decades. Some are backed by solid evidence of their effectiveness. The money should flow to them.

As a point of reference, our program, Reading Partners, is one successful literacy program. We are located in 12 metropolitan centers in 8 States and the District of Columbia. We are in 165 schools and serve 8,500 students. Reading Partners recruits and trains community volunteers to partner with students that are six months to two-and-a-half years below grade level in reading skills. The volunteers follow a highly effective research-validated curriculum in one-

on-one mentorships with the students. The program is highly successful. Over eighty-nine percent of students increased their monthly rates of literacy learning and seventy-two percent narrowed their literacy gaps with their peers. The demand for Reading Partners is growing exponentially. In schools where we are located, principals want us to increase the number of students we serve. In cities where we are located, the school superintendents want us to go into more schools. And we are also being asked to go into more cities.

As I mentioned previously, Reading Partners, while very successful, is not the only effective literacy program. However, programs like ours deserve federal support, awarded after a competitive review, to help make strides in tackling the literacy needs of the country. Again, I urge you to provide \$185 million for the Striving Reading program and to make the changes in the program I recommended.

Thank you for your consideration.



**Testimony Prepared by Erin Pulling, President & CEO of Project Angel Heart for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

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**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

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absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

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## **2.) FNS as a Care Completion Service Unique to Ryan White**

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#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

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Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

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### **Conclusion**

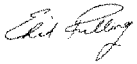


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Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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## Written Statement

Steven E. Hyman, President, Society for Neuroscience

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Subcommittee on Labor, Health, and Human Services, Education, and Related Agencies

Appropriations Committee—U.S. House of Representatives

In support of FY 2016 Appropriations for the NIH

Mr. Chairman and members of the Subcommittee, my name is Steven Hyman, and I am privileged to offer this testimony in support of increased funding for NIH for fiscal year 2016. I offer this testimony in my capacity as president of the Society for Neuroscience (SfN). I am also director of the Stanley Center for Psychiatric Research at the Broad Institute of MIT and Harvard as well as Harvard University Distinguished Service Professor of Stem Cell and Regenerative Biology. The Stanley Center is focused on using human genetic analysis to discover the neurobiological bases of neuropsychiatric disorders with a view to discovering new treatments.

The mission of SfN is to advance understanding of the brain and nervous system. Drawing on knowledge from the life sciences, physical sciences, and engineering, brain research is among the most promising and productive areas of science today. Given the tremendous human and economic toll of brain disorders worldwide, it is among those areas of research in which continued progress is most powerfully needed. On behalf of the nearly 40,000 members of SfN, I thank you for your past support of the NIH and of research. Thank you also for your support and investment in the NIH portion of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. As one crucial part of the federal investment in neuroscience, NIH-funded BRAIN programs will accelerate future discoveries across many areas of neuroscience and throughout the life sciences more broadly.

The Society stands with others in the research community in requesting \$33 billion for NIH for FY 2016. This level of support would help mitigate some of the damage done to the scientific enterprise of the United States by sequestration, which has taken an enormous toll on

the research enterprise. Following the first year of sequestration cuts in FY2013, approximately 640 fewer competitive research project grants were issued and 750 fewer new patients admitted to the NIH Clinical Center. The last four years, including 2014, have seen the lower success rates for Research Project Grants than in the previous thirteen. In recent years, funding has failed to keep pace with inflation and with the remarkable scientific opportunities that hold the potential for life-altering breakthroughs. It is time to put research on a trajectory of sustained growth that recognizes its promise and its importance as a springboard for economic development to the advancement of health and well-being for all Americans.

### **Cross-Disciplinary Neuroscience**

The basic research funded by NIH at universities and hospitals across the nation leads to discoveries that will inspire scientific and medical progress for generations. Such research also serves as a springboard for industry, which cannot take on the long-term investment or risks inherent in basic science. The following examples are a few of the many success stories made possible by research funded by a strong historic investment in NIH and other research agencies.

### **New Light on Autism, Schizophrenia, and Alzheimer's disease**

Among the risk factors for many common, devastating brain disorders, genetic contributors loom large. Identification of risk genes is critically important, because they can provide clues both to biomarkers and ideas for new therapies.

For more than a decade, it has been relatively straightforward to identify disease genes in the cases where a single gene produces illness, as in the case of familial Alzheimer's disease and some very severe forms of autism. These situations are rare, however, as illness in the vast majority of people with Alzheimer's disease, autism, and epilepsy, and virtually all people with schizophrenia, results from the interaction of many genetic variations with environmental risk

factors. While it has long been recognized that identification of the precise genetic risk factors for these disorders would be extremely valuable in the path to new treatments, such clues seemed out of reach. The human genome project changed that, providing technology and computing tools that would make it possible to identify the small genetic signals that contribute to disease, previously hidden a sea of healthy human DNA sequence variation.

Through its research support and wise policies that encouraged collaboration and sharing of data, NIH has played a central role in moving the genetic analysis of common brain disorders forward. During the past year, important progress has been reported in identifying genomic regions involved in common forms of Alzheimer's disease, autism, epilepsy, schizophrenia, and multiple sclerosis. While there remains a challenging path if we are to transform these new understandings into effective new treatments, these important newly reported clues have had a galvanizing effect in universities, hospitals, and in industry.

### **Navigating the World**

The most advanced surveillance system is built into the brain. Recent discoveries show that finding the way in the world is inexorably linked to the brain structures and processes by which memories are stored. The very same cells and circuits that help us navigate is the one that is damaged first in Alzheimer's disease. One of the first symptoms of Alzheimer's disease is that its victims can no longer find their car or their way home.

The importance of this work is underscored by the fact that the 2014 Nobel Prize in Physiology or Medicine was awarded to three pioneering neuroscientists who study navigation. Their work on the very basic science of how individual brain cells code the body's position in space has opened the door for important translational research studies. Building on this groundbreaking work, NIH-funded researchers are investigating the computations cells perform

to determine position in space; the relationship between spatial memory and decision-making; and novel interventions targeted at this system to improve cognitive abilities in a host of disorders that damage memory.

### **Bypassing Barriers**

Studies funded by NIH are helping researchers understand the blood-brain barrier, which helps block harmful substances from entering the brain. This beneficial barrier also means that an estimated 98 percent of potential drug treatments for brain disorders are unable to penetrate and work effectively.

Through techniques designed to open the barrier, doctors are able to treat brain disorders. However these techniques run the risk of also opening the brain to harmful substances. Scientists are now looking at new ways to open the blood-brain barrier in a way to allow the medicine in and keep the harmful substances out. Researchers are hopeful that research on blood-brain barrier functions and new methods for drug delivery will lead to better treatments.

### **Neuroscience: An Investment in Our Future**

Despite the difficult funding environment, the last several years have been an exciting and productive time for neuroscience discoveries. Major research advances in genomics, brain development, brain circuitry and imaging, computational neuroscience, neural engineering, and many other disciplines have occurred. Progress in these areas is leading to new tools, new knowledge, and an understanding of the brain that was unimaginable even a few years ago.

Major investment in basic and translational neuroscience is not only fueling an enduring and vital scientific endeavor; it is the essential foundation for understanding and treating diseases that strike nearly one billion people worldwide. More than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year. This, in turn, produces a

severe hardship for millions of families and costs the U.S. economy at least \$760 billion a year, with future expenses reaching the trillions looming. Advances made possible by publicly-funded research will help us maintain, and perhaps someday restore, healthy brain function. With funding from NIH, researchers can continue working towards lifesaving breakthroughs. NIH's funding should reflect the effort needed to achieve these innovations.

Additionally, NIH funding is an investment in America's current economic strength. Funding for research supports quality jobs and increases economic activity. NIH supports approximately 400,000 jobs and \$58 billion in economic output nationwide. Eighty-five percent of NIH's budget funds extramural research in communities located in every state.

Finally, without robust, sustained investment, America's status as the preeminent leader in biomedical research is at risk. Other countries are investing heavily in biomedical research to take advantage of new possibilities. Even with growing philanthropic support, the private sector cannot be expected to close the gap. The lag-time between discovery and profitability means that the pharmaceutical, biotechnology, and medical device industries need federally-funded basic (also known as fundamental) research to develop products and treatments. The foundation that basic research provides is at risk if federally-funded research declines.

## **Conclusion**

We live at a time of extraordinary opportunity in neuroscience. A myriad of questions once impossible to consider are now within reach. To take advantage of the opportunities in neuroscience, we need an NIH appropriation that allows for sustained, reliable and robust growth. That, in turn, will lead to improved health for the American public and will help maintain American leadership in science worldwide. Thank you for this opportunity to testify.

Ms. Merel Nissenberg, President, the National Alliance of State Prostate Cancer Coalitions and Mr. Tom Kirk, President and CEO of Us Too, International are providing this testimony.

Our concerns rest with the proposal of the CDC to eliminate the full \$13.205 M prostate cancer program funding in the Cancer Prevention and Control Program budget which is found in the CDC's Chronic Disease Prevention and Health Promotion budget.

Members of the committee, per recommendation of the CDC, the President's FY 2016 budget proposes elimination of 100% of the \$13.205 M annual appropriation of prostate cancer program funding in the CDC Cancer Prevention and Control budget.

Historically, this funding has been utilized in three ways: 1) by the CDC to conduct research and develop prostate cancer education and awareness materials; 2) a portion of the funding has been distributed to state cancer registries to generate prostate cancer specific information about incidence, mortality and treatment modalities; and 3) the funding has been distributed to state and local health departments as the primary source of funding for the development and administration of prostate cancer education and awareness programs.

The CDC "justifies" their proposal to eliminate funding by indicating they have "conducted extensive research on and developed materials to help doctors and other health care providers better communicate with their patients about informed decision making related to prostate



cancer screening and treatment.” They go on to say that the proposed elimination of funding “will not hinder the ability to share resources and lessons learned.”

Essentially, with their proposal to eliminate funding, the CDC asserts they have done all they need to do to develop prostate cancer education and awareness materials and there is an adequate network in our country to distribute those materials.

Our position is diametrically opposed to that of the CDC. We believe that while it appears education and awareness material developed by the CDC with prostate cancer program funding is adequate, it is evident that that prostate cancer education and awareness programs at the state level, which is where the funding is distributed for the development and implementation of such programs, are either nonexistent or at best are inadequate.

As an example, recent research shows that even though the focus of the funding for many years has been to develop and implement programs at the state health department level to train and incentivize men and their doctors to have informed discussions and make collaborative informed decisions about prostate cancer screening, treatment and quality of life options, only 4 of 50 state health departments have done so.

The consequence and perhaps greatest measure of the inadequacy of CDC education and awareness programs is that evidence-based research indicates a significant level of confusion among men and their caregivers about screening, treatment and quality of life issues; which has

recently increased as a result of the USPSTF downgrade of PSA-based screening.

This recent increase in confusion is translating into a reduction in the number of men who are receiving any type of screening at all or even seeing their physician to discuss what they should do about their prostate health; which will ultimately result in a decrease in early detection and an increase in mortality from prostate cancer.

Bottom line is that we have a serious problem with prostate cancer in this country that has been and is being exacerbated by bad screening and treatment choices resulting from a lack of awareness. This problem is not only costly in terms of the loss of life and/or reduction in quality of life, but also in terms of how much Americans and the United States Government expend on prostate cancer treatment.

Continuing and expanded prostate cancer education and awareness programs can help all Americans, and in particular men and their caregivers, have informed discussions and make informed decisions about screening, treatment and quality of life options, which in our minds will decrease the costs noted earlier in our testimony.

Members of the committee, we assert that CDC prostate cancer education and awareness programs are not at an adequate level. As a result, men are confused about their screening, treatment and quality of life options. Consequently, they are either making uninformed decisions which subsequently lead to serious complications, or they are choosing to dispense

with regular prostate care, which ultimately will lead to lower rates of early diagnosis and higher rates of mortality from prostate cancer.

Considering all of this, it clearly is not the time to eliminate funding for prostate cancer education and awareness programs as recommended in the President's F.Y. 2016 budget.

We respectfully request that leadership and members of the House - Labor HHS Appropriations Subcommittee rebuff the proposal in the President's budget and vote to retain the CDC prostate cancer program funding in the FY 2016 budget at its current level of \$13.205 M.

Thank you.



THE **AIDS** INSTITUTE

**WRITTEN STATEMENT OF  
CARL SCHMID, DEPUTY EXECUTIVE DIRECTOR, THE AIDS INSTITUTE  
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES  
HOUSE COMMITTEE ON APPROPRIATIONS  
APRIL 27, 2015**

Dear Chairman Cole and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of critical HIV/AIDS and hepatitis programs as part of the FY2016 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

**CDC Viral Hepatitis Prevention**

Before detailing our HIV requests, we would like to highlight the critical importance of doubling funding for viral hepatitis at the CDC. The CDC estimates that 5.3 million people are living with hepatitis B and/or hepatitis C in the U.S., with as many as 75 percent unaware of their infection. With new treatment options available that lead to a cure, now is the time to increase hepatitis testing, surveillance and education programs. The President's proposal of \$62.8 million for the CDC Division of Viral Hepatitis has the potential to reduce viral hepatitis transmission and prevent costly viral hepatitis-related illness and death. We urge you to support it.

HIV/AIDS remains one of the world's worst health pandemics. According to the CDC, in the U.S. over 658,000 people have died of AIDS and there are 50,000 new infections each year. A record 1.2 million people in the U.S. are living with HIV. Persons of minority races and ethnicities are disproportionately affected. African Americans, who make up just 12 percent of the population, account for 44 percent of new infections. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 200 percent of the Federal Poverty Level.

The U.S. government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting domestic HIV/AIDS efforts are funded through this Subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the federal interest as they protect the public health against a highly infectious virus. If left unaddressed, it will certainly lead to increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable health care and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent. Therefore, HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment.

The National HIV/AIDS Strategy sets clear goals and priorities, and brings the federal agencies addressing HIV together to ensure resources are well coordinated.

**The Ryan White Program**

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 536,000 low-income, uninsured, and underinsured individuals with HIV/AIDS. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 40 percent of people living with HIV in the U.S. are retained in HIV care, 37 percent have been prescribed antiretroviral treatment, and 30 percent are virally suppressed. We have a long way to go before we can realize the dream of an AIDS-free generation. With continued funding we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP), one component of the Ryan White Program, provides states with funds to pay for medications for over 200,000 people. While ADAPs continue to provide medications to Ryan White clients to keep them healthy, an increased amount of ADAP funding is being used to help low income enrollees afford insurance premiums, deductibles, and high cost-sharing related to the cost of their HIV medications.

We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

As the Affordable Care Act (ACA) is implemented, there are expanded opportunities for health care coverage for some Ryan White clients. While the ACA will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Over 70 percent of Ryan White Program clients today have some sort of insurance coverage, mostly through traditional Medicaid and Medicare. Their coverage is not changing

with health reform; the Ryan White Program will be needed as it is today. As ACA is implemented, benefits differ from state to state as not all states are choosing to expand Medicaid, and there are many gaps being filled by the Ryan White Program. Plans do not offer all of the comprehensive essential support services, such as case management, transportation, and nutritional services, that are needed to ensure retention in medical care and adherence to medications. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes—in fact, 73 percent of those in the Ryan White Program are virally suppressed. Therefore, the Ryan White Program must continue and must be adequately funded.

The AIDS Institute urges the Committee to reject the President's budget proposal to eliminate dedicated funding for Part D of the Ryan White Program and transfer it to Part C. Part D serves women, infants, children, and youth with HIV/AIDS and is a well-established system of care that has worked since 1988 in nearly eliminating mother to child transmission and providing medical care and family-centered support that helps ensure these vulnerable populations remain in care and adherent to their medications. While changes to the structure of the Ryan White Program might be needed in the future, it should not be done through the appropriations process and must include community input.

### **CDC HIV Prevention**

As a Nation, we must do more to prevent new infections, but we only allocate 3 percent of our HIV/AIDS spending towards prevention. Care and treatment costs could be eliminated if we did not have new infections. Preventing just one infection would save an estimated \$300,000 in future lifetime medical costs. Preventing all the new 50,000 cases in just one year would translate into an astounding \$15 billion saved in lifetime medical costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing resources on those populations and communities most impacted by HIV and investing in those programs that will prevent the most number of infections. One group in particular that needs additional study and resources is young black gay men, who account for 53 percent of all new HIV infections in the black community.

With over 165,000 people living with HIV in the U.S. who are unaware of their infection, the CDC is also focused on increased HIV testing programs. Testing people early allows them to be diagnosed and referred to care and treatment earlier, which is critical to bettering individual health outcomes and preventing new infections.

The CDC estimates that in 2010, 26 percent of all new HIV infections occurred among youth ages 13 to 24. Nearly 75 percent of those infections were among young gay men. We must do a better job of educating the youth, including gay youth, about HIV. Increasing funding to the HIV Division of Adolescent and School Health (DASH) will help address this need.

#### **HIV/AIDS Research at the National Institutes of Health (NIH)**

While we have made great strides, there is still a long way to go. Continued research at the NIH is necessary to learn more about the disease and to develop new treatments and prevention tools. Work continues on vaccine research and we look forward to an eventual cure.

Again, we thank you for your continued support of these programs. We have made great progress, but we are still far from achieving zero new HIV infections, an AIDS-free generation and eradicating viral hepatitis. We now have the tools, but we need continued leadership and the necessary resources to realize our goals. Thank you.





**Submitted By: Lisa Fish, MD, President, Endocrine Society**

**FY 2016 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY  
SUBMITTED BY THE ENDOCRINE SOCIETY  
FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES  
ADDRESSING THE NATIONAL INSTITUTES OF HEALTH**

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding Fiscal Year (FY) 2016 federal appropriations for biomedical research.

The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 18,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology.

**Funding for Endocrine-Related Research: An Investment in the Nation's Health**

Sustained investment by the United States federal government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists conduct research that has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries.

Endocrinologists are a vital component of our nation's biomedical research enterprise and integral to the healthcare infrastructure in the United States. Endocrine researchers study how hormones contribute to the overall function of the body, and how the glands and organs of the



endocrine system work together to keep us healthy<sup>1</sup>. Consequently, endocrinologists have a unique approach and understanding of how the various systems of the human body communicate and interact to create a comprehensive picture of health.

Endocrinologists study and treat some of the most complex disease areas, such as diabetes, obesity, bone disease, thyroid disorders, and reproductive health. Many of these conditions represent growing areas of disease burden for the United States population. NIH-funded endocrine scientists continue to make remarkable contributions in areas of critical national interest, for example:

- Endocrine scientists found a direct correlation between low vitamin D levels and impaired glucose metabolism. This study suggests that outdoor activity may also affect the risk of developing diabetes<sup>2</sup>.
- Endocrine scientists discovered how the microbes living in our intestines change as people develop diabetes<sup>3</sup>.
- Endocrine research on obesity helped develop prevention and treatments resulting in a 43% decrease in the obesity rate for children age 2 to 5 years<sup>45</sup>.

<sup>1</sup> <http://www.hormone.org/hormones-and-health/the-endocrine-system> Accessed March 19, 2015.

<sup>2</sup> Clemente-Postigo et al., "Serum 25-Hydroxyvitamin D and Adipose Tissue Vitamin D Receptor Gene Expression: Relationship With Obesity and Type 2 Diabetes." *J Clin Endocrinol Metab*. 2015 Feb 23. Electronic publication ahead of print.

<sup>3</sup> <https://www.endocrine.org/news-room/current-press-releases/gut-microbial-mix-relates-to-stages-of-blood-sugar-control> Accessed March 19, 2015.

<sup>4</sup> Casagrande et al., "The Prevalence of Meeting A1C, Blood Pressure, and LDL Goals Among People With Diabetes, 1988-2010." *Diabetes Care*, Aug 36;8 (2013) 2271-9.



### **The Future of Endocrine Research**

We are rapidly entering a new era of precision medicine. Insights into genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. Translating these new discoveries and technologies into personalized patient care offers the possibility of more effective treatments, less toxicity, increased disease prevention, improved quality of life, and lower health care costs. Several endocrine-specific conditions are on the cusp of a breakthrough in diagnostic testing. The ability to test for specific genetic mutations that cause the syndrome of resistance to thyroid hormone can dramatically alter potential treatment options. Additionally, rare adrenal tumors called pheochromocytomas and paragangliomas are notoriously challenging to diagnose. More NIH-funded basic and clinical research to help us understand how genetics can predispose us to, or protect us from disease is critical to develop and refine genetic testing strategies so that they are more reliable and more widely available.

### **Sequestration Threatens Scientific Momentum**

The Endocrine Society is particularly concerned about the impact of cuts on biomedical research supported by the NIH. At a time when we should be investing more in research to save more lives, research funding is in serious jeopardy. Since 2004, the number of NIH research grants to scientists in the United States has been declining. Consequently, the likelihood of a scientist

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<sup>5</sup> Sabrina Tavernise, "Obesity Rate for Young Children Plummets 43% in a Decade." *The New York Times*. Feb 25, 2014.



with a highly-regarded grant application successfully being awarded a new research grant has dropped from 31.5% in 2000 to 18.1% in 2014<sup>6</sup>. This means that experienced scientists are increasingly spending time writing grant applications instead of applying their expertise to productive research. Additionally, younger scientists struggle to find jobs that make use of the unique skills developed during graduate training.

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when “laboratories lose financing; they lose people, ideas, innovations and patient treatments<sup>7</sup>.” Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson’s disease, and evaluate the effect of metal contaminants on reproductive health, among many others, are delayed or terminated<sup>8</sup>.

### **FY 2016 NIH Funding Request**

The Endocrine Society recommends that the Subcommittee provide at least \$32 billion in funding for NIH in the FY 2016 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of

<sup>6</sup> [http://report.nih.gov/success\\_rates/Success\\_ByIC.cfm](http://report.nih.gov/success_rates/Success_ByIC.cfm) Accessed March 19, 2015.

<sup>7</sup> Teresa K. Woodruff “Budget Woes and Research.” *The New York Times*. September 10, 2013.

<sup>8</sup> Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. *United for Medical Research*. [http://www.unitedformedicalresearch.com/advocacy\\_reports/sequestration-profiles/](http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/) Accessed March 20, 2014.



promising research and at the same time allow the NIH's budget to keep pace with biomedical inflation.

Federal investment in the NIH and in programs such as the National Diabetes Prevention Program (NDPP) provides opportunities for substantial returns to the nation. The NDPP is based on the NIH-funded Diabetes Prevention Program clinical research study which found that even modest weight loss (5-10%) could prevent or delay the onset of type 2 diabetes by 58%. As a result of these findings, the Centers for Disease Control and Prevention (CDC) implemented the NDPP, which has now been expanded to over 794 sites in 39 states; it has been estimated that the program could save the country as much as \$191 billion if fully implemented. Moreover, 75% of these savings would benefit federal healthcare programs that provide services for seniors and the poor—individuals who share a disproportionate risk of being diagnosed with diabetes.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. The Society strongly supports increased federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status as the preeminent research engine. The Endocrine Society therefore asks that the NIH receive at least \$32 billion in FY 2016.

**Testimony of Clifford V. Harding, M.D., Ph.D., on behalf of  
The American Association of Immunologists (AAI),  
Submitted to the House Appropriations Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies,  
Regarding the Fiscal Year (FY) 2016 Budget for the National Institutes of Health  
April 27, 2015**

The American Association of Immunologists (AAI), the world's largest professional society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year (FY) 2016 appropriations for the National Institutes of Health (NIH). **AAI recommends an appropriation of at least \$32 billion for NIH for FY 2016** to fund important ongoing research, strengthen the biomedical research enterprise, and ensure that the most talented scientists, trainees, and students are able to pursue careers in biomedical research in the United States.

**NIH's Essential Role in Advancing Biomedical Research**

As the nation's main funding agency for biomedical and behavioral research, NIH supports the work of "more than 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every state and around the world."<sup>1</sup> More than 80% of the NIH budget is awarded to these scientists through nearly 50,000 competitive grants; about 10% of the NIH budget supports the work of the almost 6,000 government researchers who work in NIH laboratories or at the NIH Clinical Center.<sup>2</sup> NIH funding is a vitally important economic engine in the communities and states where these researchers work; in FY 2012, NIH funded research supported an estimated 402,000 jobs across the United States."<sup>3</sup> NIH also provides crucial scientific leadership to the entire biomedical research enterprise, both within and beyond our borders. Advancing basic research from bench to bedside requires extensive collaboration among scientists from academia, government,<sup>4</sup> and industry; all depend on NIH personnel and policies to guide and facilitate their efforts in this enormous, complicated, and high-stakes endeavor. In fact, the biotechnology and pharmaceutical industries rely heavily on NIH's investment in basic biomedical research; it is often this research that industry uses or further explores to develop new drugs and medical devices.<sup>5</sup>

### **Erosion of NIH Budget Slows Research and Threatens U.S. Preeminence**

Although NIH funds most biomedical research in the United States, its purchasing power has been dramatically reduced by inadequate budgets that have been further eroded by inflation.<sup>6</sup> In FY 2015, NIH's purchasing power is 22% lower than it was in FY 2003.<sup>7</sup> This reduced purchasing power enables NIH to fund only ~ 16.8% of grant applications submitted, a steep decline from the ~32.4% it funded when its budget was robust.<sup>8</sup> This loss is not only a barrier to advancing crucially important research, it is also devastating to those who are currently engaged in - or considering - a career in biomedical research. Researchers around the country are closing labs and losing jobs; in some cases, they are moving overseas, where support for biomedical research is rapidly growing.<sup>9</sup> Many who do stay in the U.S. are engaged in an unrelenting and time consuming search for funding, when they should be conducting research and mentoring the nation's future researchers, doctors, inventors and innovators. Most importantly of all, we will never know what research has not been pursued - or how many potential treatments and cures have not been discovered - because of inadequate funding.

### **The Immune System: Essential to our Health, Crucial to our Future**

As the body's primary defense against viruses, bacteria, and parasites, the immune system protects its host from a wide range of diseases and disorders. When it is operating properly, the immune system can provide powerful protection against many illnesses, including cancer, Alzheimer's disease, and cardiovascular disease. When it underperforms, it can leave the body vulnerable to infections, such as influenza, HIV/AIDS, tuberculosis, malaria, and the common cold. The immune system can also become overactive and attack normal organs and tissues, causing autoimmune diseases including allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Immunologists are on the front lines, therefore, working to harness the immune system to protect people and animals from chronic and acute diseases and disorders, as well as from natural or man-made infectious organisms (including Ebola, plague, smallpox and anthrax) that could be used for bioterrorism.

## **Recent Immunological Advances: Providing Hope for Today - and Tomorrow**

### ***1. Cancer Immunotherapies: Real Results in the Fight Against Cancer***

Lauded by *Science* magazine in 2013 as “The Science Breakthrough of the Year,” the genetic engineering of a cancer patient’s T cells (immune cells) to kill the patient’s own cancer cells, a procedure known as immunotherapy, continues to advance.<sup>10</sup> At NIH funded medical centers, scientists and doctors are observing a significant regression of blood cancers (non-solid tumors) in both children and adults.<sup>11</sup> This therapy, which the FDA granted Breakthrough Therapy designation in July 2014 (which can expedite approval of a therapeutic based on clear clinical efficacy), is poised to be used for even more difficult-to-treat solid tumor cancers, and is helping to inform ongoing clinical trials in breast, lung, prostate and brain cancer.<sup>12</sup> The success of these therapies has also attracted the investment of pharmaceutical companies and has led to the development of several new T cell therapy-focused biotechnology companies, illustrating how investment in NIH funded research creates opportunity - and jobs - in the private sector.

### ***2. Ebola Outbreak: Finding a Vaccine to Save Lives***

The 2014 Ebola virus outbreak in West Africa, the largest in recorded history, spread rapidly due to a lack of public health infrastructure, prophylactics, and therapeutics. Like many such diseases which have historically low rates of infection, Ebola had not attracted commercial interest. However, ongoing research by federal agencies, including NIH, provided a sufficient foundation for the development of several vaccine candidates, two of which are now being administered through clinical trials in the outbreak region and showing promising results.<sup>13</sup> Although pharmaceutical companies are now involved in manufacturing vaccines and other potential therapies, it is the federal investment in research that has made possible a rapid response to this urgent health crisis.<sup>14</sup> Because we do not know what infectious disease might emerge next, it is crucial that the federal government continue to fund basic biomedical research to ensure our ability to respond quickly, particularly when the public health benefit outweighs the potential commercial benefit.

### ***3. A New Way to Stop HIV ... and Other Infections and Diseases?***



Researchers have recently discovered that Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) systems - immune mechanisms used by bacteria to defend themselves from virus infection - present a novel therapeutic tool for immunologists, enabling them to successfully disrupt HIV replication, stop the growth of human cervical cancer cells and kill antibiotic-resistant bacteria.<sup>15</sup> Immunologists are also exploring the use of CRISPR to repair defective genes in stem cells, which may treat individuals with diseases like sickle cell anemia and immune deficiencies.<sup>16</sup>

#### ***4. New Therapeutic Provides Real Hope for Autoimmune Treatment***

In January 2015, the FDA approved the first of a new and highly effective class of treatments for psoriasis, a serious autoimmune skin disease.<sup>17</sup> The new treatment inhibits IL-17 signaling, a process which initiates inflammation and which was first discovered by NIH funded researchers in 2005.<sup>18</sup> This treatment has proven effective in Phase II clinical trials, with more than 70% of psoriasis patients showing over 75% clearance of disease, and nearly half showing 100% clearance of disease.<sup>19</sup> Clinical trials targeting similar aspects of this pathway are yielding promising results and may offer hope to those suffering from other autoimmune diseases, including ankylosing spondylitis and rheumatoid arthritis.<sup>20</sup>

### **Conclusion**

AAI appreciates the subcommittee's strong support for NIH and for ensuring a robust biomedical research enterprise in the United States, and recommends an appropriation of at least \$32 billion for NIH in FY 2016.

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<sup>1</sup> <http://www.nih.gov/about/budget.htm>. NIH funds also support the work of non-scientist technical personnel.

<sup>2</sup> Ibid.

<sup>3</sup> <http://nih.gov/about/impact/economy.htm>.

<sup>4</sup> AAI strongly opposes a federal policy that limits government scientists' ability to attend privately sponsored scientific meetings and conferences ([http://www.hhs.gov/travel/travelpolicy/2012\\_policy\\_manual.pdf](http://www.hhs.gov/travel/travelpolicy/2012_policy_manual.pdf)) and believes that "the rules have... made government scientists feel cut off from the rest of the scientific community, wreaked havoc with their ability to fulfill professional commitments, and undermined the morale of some of the government's finest minds." *Testimony (Amended) of Lauren G. Gross, J.D., on behalf of The American Association of Immunologists (AAI), Submitted to the Senate Homeland Security and Governmental Affairs Committee for the Hearing Record of January 14, 2014: "Examining Conference and Travel Spending Across the Federal Government"* ([http://aai.org/Public\\_Affairs/Docs/2014/AAI\\_Testimony\\_to\\_Senate\\_HSGAC\\_01142014.pdf](http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf)).

- <sup>5</sup> “[NIH] ... annual research funding... is the most important source of discoveries in the health sciences that ultimately leads to the development of important new therapeutics ....” Statement of Roger Perlmutter, Ph.D., Executive Vice President, Research & Development, Amgen, June 15, 2005  
<http://www.rdmag.com/articles/2005/06/managing-rapid-biotech-growth>.
- <sup>6</sup> Federation of American Societies for Experimental Biology, Funding Trends, 2015.  
<http://www.faseb.org/Portals/2/PDFs/opa/2015/2.10.15%20NIH%20Funding%20Cuts%202-pager.pdf?pdf=2.10.15%20NIH%20Funding%20Cuts%202-pager>.
- <sup>7</sup> Johnson, Judith A., “NIH Funding: FY1994-FY2016,” Congressional Research Service, R43341, pp. 2-3 (2015). Measured in constant 2012 dollars. Excludes funding from the American Recovery and Reinvestment Act (ARRA).
- <sup>8</sup> Research Project Grant Award Rate (“the likelihood of an individual application submission getting funded”). Rockey, Sally, “Comparing Success Rates, Award Rates, and Funding Rates,” *Rock Talk*, March 5, 2014. RPG success rates (“the number of awards made divided by the sum of the applications reviewed that fiscal year where revisions submitted in the same fiscal year are collapsed and counted as one application”) have also decreased drastically, from 32.4% to 18.1%. See <http://nexus.od.nih.gov/all/2014/03/05/comparing-success-award-funding-rates/>.
- <sup>9</sup> Moses, H., *et al.* The Anatomy of Medical Research: US and International Comparisons. *JAMA* 313, 174-189 (2015). According to Moses *et al.*, while U.S. funding for biomedical and health services research increased at a rate of 6 percent per year from 1994-2004, it decreased to just 0.8 percent annually from 2004-2012.
- <sup>10</sup> Couzin-Frankel, J. Cancer Immunotherapy. *Science* 342, 1432–1433 (2013).
- <sup>11</sup> Maude, S. L. *et al.* Chimeric antigen receptor T cells for sustained remissions in leukemia. *N. Engl. J. Med.* 371, 1507–1517 (2014).
- <sup>12</sup> Kakarla, S. & Gottschalk, S. CAR T Cells for Solid Tumors: Armed and Ready to Go? *Cancer J.* 20, 151-155 (2014)
- <sup>17</sup> See <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm430969.htm>.
- <sup>13</sup> See <http://www.niaid.nih.gov/news/newsreleases/2015/Pages/PREVAIlphase2.aspx>.
- <sup>14</sup> Wong, G., *et al.* Intranasal immunization with an adenovirus vaccine protects guinea pigs from Ebola virus transmission by infected animals. *Antiviral Res.* 116, 17–19 (2015); Stanley, D. A. *et al.* Chimpanzee adenovirus vaccine generates acute and durable protective immunity against ebolavirus challenge. *Nat. Med.* 20, 1126–1129 (2014).
- <sup>15</sup> Hu, W. *et al.* RNA-directed gene editing specifically eradicates latent and prevents new HIV-1 infection. *Proc. Natl. Acad. Sci. U. S. A.* 111, 11461–11466 (2014); Kennedy, E. M. *et al.* Inactivation of the human papillomavirus E6 or E7 gene in cervical carcinoma cells by using a bacterial CRISPR/Cas RNA-guided endonuclease. *J. Virol.* 88, 11965–11972 (2014); Citorik, R. J., *et al.* Sequence-specific antimicrobials using efficiently delivered RNA-guided nucleases. *Nat. Biotechnol.* 32, 1141–1145 (2014).
- <sup>16</sup> Huang, X. *et al.* Production of gene-corrected adult beta globin protein in human erythrocytes differentiated from patient iPSCs after genome editing of the sickle point mutation. *Stem Cells* (2015). doi:10.1002/stem.1969.
- <sup>18</sup> Langrish, C. L. *et al.* IL-23 drives a pathogenic T cell population that induces autoimmune inflammation. *J. Exp. Med.* 201, 233–240 (2005).
- <sup>19</sup> Gaffen, S. L., *et al.*, The IL-23-IL-17 immune axis: from mechanisms to therapeutic testing. *Nat. Rev. Immunol.* 14, 585–600 (2014).
- <sup>20</sup> See <http://www.novartis.com/newsroom/media-releases/en/2014/1864939.shtml>.

To: U.S. House Subcommittee on Labor, HHS, Education and Related Agencies Appropriations  
From: Dr. Lisa Simpson, President & CEO, AcademyHealth  
Re: FY 2016 Funding for Health Services Research & Health Data at AHRQ, NCHS, NIH

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AcademyHealth is pleased to offer this testimony regarding funding for federal agencies that support health services research and health data, including the Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics (NCHS), and the National Institutes of Health (NIH). AcademyHealth works to improve health and the performance of the health system by supporting the production and use of evidence to inform policy and practice. We represent the interests of more than 5,000 health services researchers, policy analysts, and practitioners that produce and use health services research to improve our nation's health and the performance of the health care and public health systems. For FY 2016, we recommend funding levels of \$375 million for AHRQ, \$172 million for NCHS, and at \$32 billion for NIH.

The United States spent \$2.9 trillion—17.4 percent of our economy—on health care in 2013. Finding new ways to get the most out of every health care dollar is critical to our nation's long-term fiscal health. Like any corporation making sure it is developing and providing high quality products, the federal government—as the nation's largest health care purchaser—has a responsibility to get the most value out of every taxpayer dollar it spends on Medicare, Medicaid, Children's Health Insurance Program, and veterans' and service members' health.

Health services research is our nation's R&D enterprise for health improvement. Just as medical research discovers cures for disease, health services research discovers cures for the health system (see Figure 1). This research diagnoses problems in health care and public health delivery and identifies solutions to improve outcomes for more people, at greater value. And while biomedical and clinical research discoveries can take years and even decades to reach patients, discoveries from health services research can be used now by patients, health care providers, public health professionals, hospitals, employers, and public and private payers to improve care today.

Put plainly, health services research helps Americans get their money's worth when it comes to health care. We need more of it, not less. Despite the positive impact health services research has had on the U.S. health care system, and the potential for future improvements in quality and value, the United States spends less than one cent of every health care dollar on this research; research that can help Americans spend their health care dollars more wisely and make more informed health care choices.

AcademyHealth realizes the pressure Congress and the administration face to reduce the national debt. We respectfully ask that the subcommittee consider the value of health services research in achieving that goal, and to strengthen its capacity to address the pressing challenges America faces in providing access to high-quality, efficient care. The following list summarizes AcademyHealth's FY 2016 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

#### **Agency for Healthcare Research and Quality**

AHRQ is the only federal research agency with the sole purpose of producing evidence to make health care safer; higher quality; more accessible, equitable, and affordable; and to ensure that the evidence is understood and used. AHRQ funds health services research and health care improvement programs in universities, medical centers, research institutions, hospitals, health clinics, and medical practices that are transforming people's health in communities in every state around the nation. The science funded by AHRQ provides consumers and their health care professionals with valuable evidence to make health care decisions. For example, medical societies use AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes and rheumatoid arthritis. These evidence-informed recommendations give physicians a foundation for describing what the best care looks like, so millions of patients living with these and other conditions may determine what the right care might be for them.

AHRQ's research also provides the basis for strategies that improve patient safety and health outcomes. For example, adverse events—hospital acquired infections, falls pressure ulcers, and

adverse drug events—declined by 17 percent between 2010 – 2013, with 1.3 million fewer adverse events and an estimated 50,000 fewer deaths and \$12 billion in cost savings.

AcademyHealth joins the Friends of AHRQ—an alliance of health professional, research, consumer, and employer organizations that support the agency—in recommending \$375 million in budget authority for AHRQ in FY 2016.

### **National Center for Health Statistics**

NCHS is the nation’s principal health statistics agency. Housed within the Centers for Disease Control and Prevention (CDC), it provides critical data on all aspects of our health care system through data cooperatives and surveys that serve as a gold standard for data collection around the world. AcademyHealth appreciates the subcommittee’s support of NCHS in recent years. Such efforts have allowed NCHS to reinstate data collection and quality control efforts, continue the collection of vital statistics, and modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—an alliance of health professional, research, consumer, industry, and employer organizations that support the agency—in recommending an overall funding level of \$172 million for NCHS in FY 2016. This includes \$160 million in budget authority and \$12 million in mandatory Prevention and Public Health Fund. This funding level will support the agency’s core data collection activities, as well as new initiatives to enhance death data timeliness and security, restore survey expansions to better assess access to and utilization of health care services

### **National Institutes of Health**

NIH spends approximately \$1 billion on health services research annually—roughly 3 percent of its entire budget—making it the largest federal sponsor of health services research. We join the research community in seeking at least \$32 billion for NIH in FY 2016. NIH has an important role in the federal health services research continuum, and is well-positioned to ensure that discoveries from clinical trials are effectively translated into health care delivery.

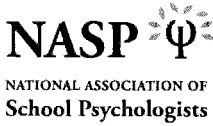
AcademyHealth supports efforts to help NIH foster greater coordination of its health services research investment among its institutes and across other federal agencies to avoid duplication. Given the 30th anniversary this year of the landmark Heckler Report on Black and Minority Health, we note the importance of research to eliminate health and health care disparities being conducted throughout the Department of Health and Human Services and our support for the mission of NIH's National Institute for Minority Health and Health Disparities.

AcademyHealth also recommends that the Clinical and Translational Science Awards (CTSA) through the National Center for Advancing Translational Sciences (NCATS) sustain investment in the full spectrum of translational research (T1-T4). The CTSA program enables innovative research teams to speed discovery and advance science aimed at improving our nation's health. The program encourages collaboration in solving complex health and research challenges and finding ways to turn their discoveries into practical solutions for patients. Finally, AcademyHealth supports continued investment by NIH and its many Institutes and Centers in dissemination and implementation research. This research helps us understand which approaches work to improve population health.

In conclusion, the accomplishments of the field of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee gives strong consideration to our FY 2016 funding recommendations for the federal agencies funding health services research and health data. If you have questions or comments about this testimony or wish to know more about health services research, please contact Dr. Lisa Simpson, President and CEO of AcademyHealth, at 202.484.1100 or [lisa.simpson@academyhealth.org](mailto:lisa.simpson@academyhealth.org).

Figure 1: The Health Research Continuum			
<i>These components of the health research continuum work in concert, and each plays an essential role—any one type of research on its own cannot effectively or appreciably improve health. Take heart disease as one example...</i>			
<b>Basic research</b> discovered the contributions of elevated blood pressure, elevated cholesterol, and tobacco use to heart disease.	<b>Clinical research</b> determined which treatments were safe and effective to treat hypertension, hypercholesterolemia, tobacco addiction, and to prevent and treat heart disease, in general.	<b>Population-based research</b> identified strategies to reduce the risks of heart disease in communities through non-medical interventions, such as reduction of trans fats in food and tobacco control measures to reduce smoking.	<b>Health services research</b> determined how to best deploy these discoveries to achieve the best health outcomes. This research helped identify who had the least access, what barriers existed, and how to mitigate them. This research also led to the development of quality measures that are now used to report on the quality of cardiac care.

Source: *AHRQ: 15 Years of Transforming Care and Improving Health*, AcademyHealth, Jan. 2014. Available at: <http://academyhealth.org/files/AHRQReport2014.pdf>



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The Honorable Tom Cole  
Chairman  
Appropriations Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
Washington, DC 20515

The Honorable Rosa DeLauro  
Ranking Member  
Appropriations Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
Washington, DC 20515

April 27, 2015

Dear Chairman Kingston and Ranking Member DeLauro:

On behalf of the National Association of School Psychologists, I respectfully request you provide \$75 million for the Elementary and Secondary School Counseling Program (ESSCP) for Fiscal Year 2016. This program is operated by the Department of Education's office of Safe and Healthy Students and is the *only* federal program devoted to creating and expanding comprehensive school counseling programs in schools. ESSCP provides funds to school districts that demonstrate the greatest need for new or additional school counseling services, the greatest potential for replication or dissemination, or for programs that are the most innovative. ESSCP also allows schools to hire school counselors, school psychologists, and school social workers to ensure students have access to services and supports that promote optimal conditions for learning, improve school climate, improve school safety, and ultimately student learning.

ESSCP contains a statutory funding trigger, which prevents funds from being used for secondary school programs unless total funding exceeds \$40 million, with that base amount reserved for elementary schools. This funding trigger has been met each year since FY 2008, which has allowed middle and high schools to apply for grants. Comprehensive counseling programs in secondary schools help to improve attendance, reduce truancy and drop-out rates, and provide students with college and career counseling as



they transition into adulthood. Increasing funding to \$75 million will allow funding for secondary schools at a level similar to what is available to elementary schools.

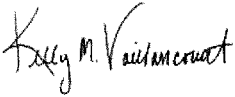
Each day, students come to school with a wide variety of social, emotional, and behavioral issues that can at times impact their ability to reach their full academic potential. School counselors, school psychologists, and school social workers are the most qualified professionals to address these issues. These professionals are uniquely trained to work in schools, with staff and parents, and understand the critical link between school safety, students' emotional wellness, and their academic achievement. Furthermore, these school-employed professionals work to maximize resources by coordinating programs and services between schools and the community. They collaborate to provide comprehensive counseling services that address barriers to learning and help students develop the communication and social skills required to be successful across the lifespan. The ESSCP allows schools to support high quality instruction with high quality counseling services to promote maximum student success. ESSCP is an effective program that already has statutory authorization and can help many schools and districts implement or expand school counseling programs to improve school safety, improve student access to mental health, and ultimately improve student achievement. There is bi-partisan support for this program, most recently evidenced by the statutory authorization of ESSCP in the Senate HELP Committee mark of the *Every Child Achieves Act of 2015*. Failure to fund this program would be a significant loss for schools and ultimately students.

Currently ratios of the three professions to students far exceed the recommendations of the professional organizations that represent them. These extraordinarily high professional to student ratios make it extremely difficult to deliver high quality, comprehensive counseling services in schools. The ESSCP is filling a void in those schools with the greatest need for counseling and mental health services, and the demand for the funding provided by this program is overwhelming. The Department of Education consistently receives approximately 10 times more applications than they can fund. As a result, the Department only requests new grant applications every two years. ESSCP has been funded at \$49.5 million

for FY 2013, FY 2014, and FY 2015. The Department awarded 41 new grants in FY 2014 and will be announcing the FY 2015 recipients in the near future.

I understand these are difficult economic times; however, we urge you to increase the funding to \$75 million for the ESSCP to improve outcomes for all students. Thank you for your time and attention to this matter.

Respectfully,

A handwritten signature in black ink that reads "Kelly M. Vaillancourt". The signature is written in a cursive, flowing style.

Kelly Vaillancourt, PhD, NCSP  
Director, Government Relations  
National Association of School Psychologists  
kvaillancourt@naspsweb.org

**Testimony of Stephen DeWitt**

**Deputy Executive Director**

**Association for Career and Technical Education**

**Subcommittee on Labor, Health and Human Services, Education, and Related**

**Agencies**

**Committee on Appropriations**

**U.S. House of Representatives**

**April 29, 2015**

Chairman Cole, Ranking Member DeLauro and members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), the nation's largest not-for-profit association committed to the advancement of education that prepares youth and adults for successful careers, I would like to urge you to help support career and technical education (CTE) through a strong federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for Fiscal Year (FY) 2016. The passage of the Bipartisan Budget Act and subsequent Consolidated Appropriations Act of 2014 helped to alleviate some of the harmful sequestration cuts that have impacted important career education and workforce training programs, but more needs to be done to support our high schools, technical centers, community

colleges and millions of CTE students nationwide. To ensure that students are equipped with the academic, technical and employability skills they need for success in the jobs that are available today, and the careers of tomorrow, I respectfully request that the subcommittee restore the Perkins Basic State Grant program (Title I), administered by U.S. Department of Education, Office of Career, Technical, and Adult Education, to at least the pre-sequestration level of \$1.123 billion in the FY 2016 Labor, Health and Human Services, and Education appropriations bill.

Perkins is the principal source of federal support for CTE programs in secondary and postsecondary institutions across the country. This federal investment is crucial to ensuring that students are prepared for careers in expanding fields like engineering, information technology, advanced manufacturing and health care. In a rapidly changing job market, CTE provides students with transferable skills that ensure they are college- and career-ready, while offering retraining opportunities to many adult or dislocated workers.

Perkins is the foundational support for CTE program improvement and a strong CTE investment is essential to moving our economy forward. However, funding has not kept pace with the demand for high-quality programs. In FY 2015, Congress appropriated over \$140 million less in Perkins grant funding to states than it did in FY

2010. From FY 2007 through FY 2014, total Perkins grant funding to states declined by 13 percent (a 23 percent decline when adjusted for inflation). A recent survey found that 9 out of 10 career and technical educators rely on Perkins to support their CTE program, but more than half of CTE educators say their program budget has decreased in recent years. Perkins funding is an essential component in allowing education providers to build the capacity necessary to serve more than 12 million secondary, postsecondary and adult students nationwide.

The erosion of Perkins funds comes at a time when CTE programs are experiencing new attention and growth. States are using Perkins funding to achieve positive results—meeting or exceeding nearly every accountability target for student performance in areas such as attainment of academic and technical skills, and transition to further education or employment. In the most recent comparable data available, the average high school graduation rate for students concentrating in CTE programs is 93 percent, compared to a national adjusted cohort graduation rate of 80 percent. This national data is borne out on the ground where students involved in CTE programs are more engaged in their education, perform better academically, gain critical employability skills and earn industry-recognized credentials. Perkins provides a strong return on our federal investment by fostering an educated and highly skilled workforce that delivers

direct benefits to American employers, further strengthening the economy through productivity and innovation.

The Obama Administration's FY 2016 budget request includes the addition of \$200 million for a CTE Innovation Fund within the Basic State Grant, which would support the proposed American Technical Training Fund by providing competitive grants to support the development and operation of innovative, evidence-based job training programs in high-demand fields. The additional request of a \$2 million increase for CTE National Programs would provide technical assistance and evaluation support for projects under the American Technical Training Fund proposal. While these resources would help meet the needs of a few programs, the Administration's budget, once again, fails to provide any additional funding for the formula Perkins Basic State Grant program. It is the position of ACTE that limited resources for education and job training are better directed to proven, formula-driven programs that reach all communities, and we remain committed to expanding equitable access to high-quality CTE. Congress must fulfill its commitment to America's students, employers and educators by increasing its investment in CTE through Perkins.

Sequester level nondefense discretionary funding caps have been, and continue to be a significant obstacle to bringing much need resources to education and job training

programs, including Perkins. Further compounding the situation, the recently approved FY 2016 302(b) allocation for this subcommittee is \$3.7 billion (or 2.4 percent) less than the FY 2015 level. This is an unsustainable budget framework that places the burden of fiscal austerity disproportionately on programs under the jurisdiction of this subcommittee. It is our hope that Congress will work toward a balanced approach to provide relief from sequestration in FY 2016 and beyond. By addressing the need for additional funding for nondefense discretionary programs overall, Congress can create new opportunities to build our investment in CTE.

Thank you for your continued leadership and for your thoughtful consideration of our request. We look forward to working in a bipartisan fashion with the subcommittee throughout the FY 2016 appropriations process.



**Testimony Prepared by Greg Lukeman, Executive Director of Food Outreach, Inc. for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Food Outreach, Inc. is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 560,000 medically tailored, home delivered meals annually to 2,100 clients. Our clients live in 187 Missouri and Illinois zip codes. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase



absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public

insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

## Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### 4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

## Conclusion

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and

reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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<sup>1</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

<sup>2</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>3</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>4</sup> Ibid.

<sup>5</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

<sup>6</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>7</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

<sup>8</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

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<sup>95</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

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# neuac

National Energy and Utility  
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**House Committee on Appropriations Subcommittee on Labor,  
Health and Human Services, Education and Related Agencies**

**Written Testimony of  
The National Energy and Utility Affordability Coalition (NEUAC)**

**Regarding The  
FY16 U.S. Low Income Home Energy Assistance Program (LIHEAP)**

The U.S. Low Income Home Energy Assistance Program (LIHEAP) is America's cornerstone energy safety net program, within the jurisdictional responsibility of this Subcommittee. LIHEAP is federally administered by the U.S. Department of Health and Human Services, Administration of Children and Families, Office of Community Services. It is presently funded

at \$3.39 billion. NEUAC urges that LIHEAP be restored to earlier levels of at least \$4.7 billion for FY2016.

Why the need for more funding? In FY14 LIHEAP served just 19.37 percent of qualifying U.S. households, well under the federal income eligibility limits. Of total U.S. households of 114.8 million, those that subsist at or below 60 percent of median income or 150 percent of poverty income comprise 35.1 million U.S. households.

NEUAC has determined that in FY2014 LIHEAP actually reached and provided some form of assistance to 6,803,652 U.S. households. This means that overall, 81 percent of U.S. households meeting the federal standard were not served in FY2014. The highest percentage served was achieved in New York State (at 50 percent of eligible). The lowest was in Texas (where just 4 percent were reached, and 96 percent were not).

LIHEAP is not an entitlement, it must come before Congress every year and no one is assured of assistance, not even households in crisis. LIHEAP recipients must seek assistance and their need must be documented. Since 2009, LIHEAP funding has been reduced by one third, but the need has not fallen by a similar measure. Congress has entrusted the states to set income eligibility levels up to 60 percent of median income or 150 percent of the Federal poverty guideline. Due to funding constraints, many states set the bar substantially below these thresholds. States are

authorized to address heating, cooling or crisis situations and at their sole discretion, they are also able to target a portion of funds to weatherize qualified homes.

Generally, those who need the help are served on a first-come, first served basis, but Congress also has directed the states to prioritize households with at-risk residents, such as elderly, disabled or children under six-years-old. Additionally, frontline providers have observed that the program is also now serving increasing numbers of U.S. military veterans.

In instances where LIHEAP cannot adequately address the real need, state and local administrators are compelled to explain that available funds are simply no longer available. This past January, in five east Kentucky counties, LIHEAP Crisis funds were made available and depleted in just over two weeks, leaving several months of extreme cold and high bills for the remainder of winter and into spring. A large local energy assistance provider in Arkansas stopped accepting applications March 20<sup>th</sup> leaving the possibility of high bills from winter to pile up for many struggling families and seniors.

And finally, LIHEAP doesn't just help people through tough times, it can be a life saver and the lack of assistance can be deadly. Earlier this month a Princess Anne, Maryland father and his seven children died of carbon monoxide poisoning from a generator left on overnight to heat his



home. Rodney Todd was struggling to provide for his family and could not afford to turn on his utility service.<sup>1</sup>

Anecdotal evidence such as these instances, highlight the unmet need on a program that has borne reductions since 2009 and created an untenable strain on vulnerable households and assistance providers. We therefore urge the Subcommittee to fully and fairly fund this program, free of encumbrances in FY2016 at the level of \$4.7 billion.

NEUAC notes that while the Administration seeks level funding in FY2016, and even holds out the potential of an automatic commitment of additional resources in exceptional circumstances, this Budget request establishes new requirement to withhold funds to accommodate up to twenty new “competitive utility grants” and requiring that at least 10 percent of LIHEAP resources be committed to weatherization.

NEUAC’s position is that while both proposals are well-intentioned; they have the practical effect of reducing the commitment of core LIHEAP resources to states, tribes and their nonprofit bill payment partners. Thus, NEUAC opposes both proposals, and urges the Subcommittee to maximize its commitment to LIHEAP, to concentrate all resources into the program’s Base

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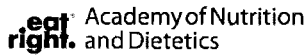
<sup>1</sup><http://time.com/3773584/carbon-monoxide-family-poisoning/>

grants, and to enable the program to focus upon the core mission Congress established it to accomplish.

Thank you for the opportunity to express the views of the National Energy and Utility Affordability Coalition on this important matter. On behalf of the 6.8 million households that were helped in 2014, we thank you for consideration of our request to fund LIHEAP at an amount no lower than \$4.7 billion in FY2016.

###

The National Energy and Utility Affordability Coalition (NEUAC) and its diverse membership of fuel funds, community action and human service agencies, faith-based service providers, utilities, tribal communities and state and local government organizations is dedicated to heightening awareness of and better addressing the energy needs of America's low- and moderate income households.



**Testimony Prepared by the Academy of Nutrition and Dietetics, for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Academy of Nutrition and Dietetics is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. The Academy is the world's largest organization of food and nutrition professionals, and is committed to improving the nation's health with nutrition services and interventions provided by registered dietitian nutritionists. Nationwide, The Academy has over 75,000 members. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids

and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

#### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

#### 4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

#### Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library. Please feel free to contact me at 312.899.1731 or [mrainmondi@eatright.org](mailto:mrainmondi@eatright.org) with any questions on these important issues. Thank you again for your time.

Sincerely,

*Mary Pat Raimondi MS, RD*

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<sup>i</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

<sup>ii</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>iii</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>iv</sup> Ibid.

<sup>v</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

<sup>vi</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>vii</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, J Prim Care Community Health, 4(4):311-7 (June 3, 2013)

<sup>viii</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, J Prim Care Community Health, 4(4):311-7 (June 3, 2013)

<sup>ix</sup> Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434-438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371-374.

<sup>x</sup> M. S. Cohen *et al.*, "Prevention of HIV-1 Infection with Early Antiretroviral Therapy," *N. Engl. J. Med.* **365**, 493-505 (2011). HPTN 052

<sup>xi</sup> Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141<sup>st</sup> Annual Meeting, Boston, MA, November 5, 2013.

<sup>xii</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

<sup>xiii</sup> Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14-20. doi: 10.1007/s11606-008-0824-5. Epub 2008 Oct 25.

Testimony Submitted by  
John Arch  
Executive Vice President of Health Care  
Boys Town National Research Hospital

**Recommendation:** Mr. Chairman, our request of the Subcommittee is two-fold:

- We urge you to encourage NIMH, NICHD and NIDA to expand research, including ongoing intramural research, to advance the biological evidence-base of psychosocial interventions that can be used instead of, or in combination with, psychotropic medications.
- We also ask that CMS be urged to support research into reasons for this disparity, including whether current reimbursement policy incentivizes reliance on medication rather than evidence-based psychosocial therapies instead of, or in combination with, psychotropic medications.

Chairman Cole, Ranking Member DeLauro and Members of the Subcommittee-

I am honored to represent Boys Town, an institution founded in Omaha, Nebraska, in 1917 by Father Edward Flanagan. Boys Town provides care to youth in eleven states, directly serving more than 74,000 children each year. While Boys Town cares for a large number of children, our mission is more far-reaching. Our objective is to change the way America cares for children, families, and communities. That is the goal that shapes everything we do, including our efforts to address the national concern regarding the appropriate use of psychotropic medication in the treatment of children with behavioral and mental health problems.



Boys Town provides many services for children and families including residential care, family counseling, foster care, and in-home services. We also provide medical care and conduct medical research at Boys Town National Research Hospital in Omaha, focusing on communication disorders and behavioral and psychiatric disorders in children. I am responsible for the health care division which serves 45,000 children annually, including the most troubled children cared for by Boys Town in our Residential Treatment Center. Since opening the center in 1996, we have treated children from 38 states.

The Boys Town Residential Treatment Center is changing the lives of children ages 5 to 18 who have severe behavioral and mental health problems through a proven medically-directed treatment program. Our goal is to help children gain the self-control and self-confidence necessary to achieve their goals and become productive members of society. Our treatment program is specifically designed to offer medically-directed care for more seriously troubled youth who require supervision, safety and therapy.

Our model of care is very behavior-focused. Children spend each day with specially trained and motivated staff that teaches them appropriate behavior to replace individual problem behaviors identified when a child enters the program. They are also taught self-control options to be used in times of stress or in situations where they have historically used inappropriate coping behavior.

Approximately 79 percent of the children who are admitted to our Treatment Center have been prescribed multiple psychotropic medications at the time of admission, with some taking as many as eight medications to control their behavior. We are very concerned with the lack of

scientific evidence regarding the safety and efficacy of these drugs in young patients, and are especially concerned about the potential long-term effects on their development. Despite the lack of research regarding their effectiveness, and evidence of serious adverse effects, psychotropic medication rates have drastically increased in behaviorally disordered children since the early 1990s.

To address these issues, Boys Town convened a diverse group of researchers, physicians, human service organizations and other child advocates in 2011 for a two-day National Institute of Mental Health (NIMH)-funded conference on the use of psychotropic medications with youth in residential care settings.

Going forward, research teams who participated in this conference will examine the forces that drive the current high medication rates, evaluate best practices for taking children off the medications when appropriate, and define effective management of medication use within the context of other treatments. It was apparent from this conference and other sources that additional research is needed to address many of these issues. In response, Boys Town launched a new research initiative with its Center for Neurobehavioral Research in Children, located at Boys Town National Research Hospital. Our Center's mission is to advance the evidence base for safer and more effective interventions for children.

We could come up with lots of reasons why our foster children are being overmedicated: not enough time, not enough money, lack of qualified medical personnel, lack of alternative treatment. But, in the end, there simply is no excuse. There are children in the foster care system who are facing serious mental health concerns – anxiety, depression, and worse – and

for these children medication can be a tremendous benefit. But, given the lack of evidence of the safety and efficacy of these medications in young children, alternative treatments need to be aggressively pursued for those who can benefit. Juvenile courts need to be closely involved in the process to ensure that the child's voice is heard and interests are served. We also need to ensure that each and every child in foster care has the support of a caring adult who can look after his or her best interests, including monitoring and when necessary, raising concerns about medication and health care.

Psychiatric residential treatment services can play several effective roles within the overall system including: a) intensive treatment while maintaining safety, b) a component of a step up/step down plan for a child, c) treatment of serious disorders that require coordinated multimodal interventions, d) assessing medication level while providing a stabilizing environment, e) alternative to psychiatric hospitalization, and f) a treatment of last resort for children for whom other interventions have been ineffective.

Not too long ago, we treated a young man who had been in and out of the mental health system several times. He had extreme temper issues and eventually was arrested for assault. The judge referred him to our Treatment Center. At the time admitted, he weighed more than 300 pounds and was taking multiple psychotropic medications prescribed by different physicians. During his stay, he was tapered off several of his medications and the level of the other medications was reduced. With treatment and appropriate medication, he improved and was placed into one of Boys Town's residential family homes where he went on to graduate from high school near the top of his class and enrolled at a local university to study engineering.

He is but one of many youth whose life trajectory has been changed to allow them to become productive citizens.

With our approach, we have been able to achieve a significant reduction in medication among the children we treat. A recent study conducted at our Treatment Center, utilizing a medication management program within the structure of our strong behavioral treatment model, demonstrated a 33 percent reduction in the number of youth on any psychotropic medication and a 38.2 percent reduction in the average number of medications being prescribed at the time of discharge. The study was a part of a nationwide research project conducted by Boys Town in collaboration with other organizations. Children are succeeding with our treatment model, but our mission at Boys Town compels us to do more.

It is our hope that our new Research Center will help us to develop the biological evidence base to support safer and more effective interventions for children and reduce our reliance on medications.

Thank you for the opportunity to submit this testimony. We stand ready to assist the Subcommittee in whatever way we can.



## Seattle Indian Health Board

*For the Love of Native People*

TESTIMONY OF AREN SPARCK  
GOVERNMENT AFFAIRS OFFICER  
SEATTLE INDIAN HEALTH BOARD  
FOR

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE  
ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES  
April 2015

Chairman Cole, Ranking member DeLauro and Representatives of the Subcommittee on Labor, Health and Human Services (HHS), Education, and Related Agencies, my name is Aren Sparck. I am the Government Affairs Officer for the Seattle Indian Health Board (SIHB), which is a contractor and grantee with the Indian Health Service (IHS), and one of the largest of the 33 Subchapter IV of the Indian Health Care Improvement Act (IHCIA) funded Urban Indian Health Programs (UIHP). We provide primary care services as a Health Resources Services Administration 330 program, offer outpatient services on-site, and operate the Thunderbird Treatment Facility, a 65-bed inpatient chemical dependency treatment center. We also create, analyze, and report on urban Indian health data through our Urban Indian Health Institute (UIHI), the only IHS Tribal Epidemiology Center (TEC) in the country with a national purview. We are asking for \$5 million for urban American Indian/Alaska Native (AI/AN) health research funds over 5 years.

I am requesting that the Subcommittee increase their investment in monitoring the health status of the urban AI/AN population. Since 1970, the urban AI/AN population has grown from 45%<sup>1</sup> of all AI/ANs to 71%<sup>2</sup> in 2010. The urban AI/AN health line item was less than 1%<sup>3</sup> of the overall IHS budget in FY2015, with a flat increase in the President's FY2016 budget. There were negligible allocations from other federal trust obligation areas of housing and education to address the needs of the urban population. Considering this, it is easy to see that the urban AI/AN population suffers alarmingly high rates of disparities, notably in poverty, unemployment, a lack of health insurance, etc.<sup>4</sup> Despite UIHPs and urban AI/AN serving institutions receiving legislative authority in Subchapter IV<sup>5</sup> (formerly Title V) of the IHCIA, as amended in 2010 in the Patient Protection and Affordable Care Act (PPACA), a lack of inclusion in program and resource planning committees at the HHS level has resulted in the majority of funds going to tribes where approximately two out of every 10 AI/ANs live in tribal lands.<sup>2</sup> The FY2015 IHS budget urban line item was \$46.3 million dollars<sup>3</sup>, again less than 1% of the total IHS budget, despite seven out of every 10 AI/ANs living in urban areas.<sup>2</sup> We feel that the almost discriminatory lack of resource and administrative attention the urban AI/AN population receives can be attributed to a lack of inclusion in program-planning at the federal level, and a lack of quality data for reference. This is the reason we are asking the Subcommittee to invest

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not just in funds, but administration –wide, so a more complete picture of AI/AN community health can be achieved. We feel that with increased investment from HHS, the IHS budget shortfall for the urban population will be better addressed with sound science and data.

We recently had a conversation with the Director of the Office of Minority Health (OMH) about the importance of increasing their monitoring investment for urban AI/ANs. What we heard from the director was, unfortunately, what we have heard from every department head in HHS. They absolutely do understand the overrepresentation in population and underrepresentation in research dollars allocated to the urbans, but the resources are just not there to address the disparities.

Because the urbans receive so little attention from HHS and the OMH, we have very little baseline data concerning where the 71% of urban AI/ANs are accessing healthcare and what types of services they are utilizing. We know that our urban AI/AN population suffers from high rates of health disparities in multiple chronic conditions,<sup>4,6</sup> but the UIHPs that are tasked with delivering health care to the 3.7 million AI/ANs living in urban areas are only in 19 states and 100 counties.<sup>7</sup> In the UIHP catchment areas, there are one million AI/ANs we can have potential access to,<sup>8</sup> but the reality is, we see a small fraction of that. In SIHB's catchment area of King County, the most urban and populated county in the state of Washington, there are approximately 40,000 AI/ANs<sup>9</sup>, and we see only 3,889.

Knowing where our population is going for healthcare, and what types of services they are utilizing pre- and post- healthcare reform implementation will help us understand whether: 1) the quality of national data sets, such as the Epi Data Mart, UDS and CMS data are creating a comprehensive picture of urban AI/AN health; 2) chronic conditions are being treated; 3) primary and preventative care are being accessed; 4) access to the IHS, Tribal Health and UIHP (I/T/U) system of culturally relevant care make a difference in health status; and 5) the policy intervention the PPACA implemented is truly making a difference in the AI/AN population.

To do this, we are asking that the Subcommittee allocate \$5 million in research funds over five years to the OMH specifically for the analysis of where urban AI/ANs are accessing care throughout the country and what types of services they are utilizing. This is the baseline data that will allow us to make better policy decisions about where research and program funds go in Indian Country to end the high health disparities our urban population experiences. We also ask that the funds go to an AI/AN research organization such as the TECs that have experience collecting and analyzing national data. This will help build the scientific and infrastructure capacity within our AI/AN community necessary to create a trusting partnership between HHS and Indian Country by legitimizing quality research and data analysis for AI/ANs by AI/ANs. This is preferable to seeing research dollars build the capacity of academic institutions whose primary focus is not in Indian Country.

Aside from the \$5 million for urban AI/AN healthcare access and service utilization analysis, we ask that funding priorities reflect less understood and emergent issues our urban population is facing. Because our urban population is by and large highly mobile and low-income, social and health pressures are exerting themselves in our urban AI/AN youth that are vulnerable to conditions of mental health and chemical dependency problems, violence and an alarming incidence of prostitution and human trafficking. Our youth are very susceptible to gang violence, as the family and cultural dynamic is often disparate and inconsistent due to a lack of any dominant AI/AN culture in the city. A special funding emphasis needs to be made addressing dental health and access to specialty care for our population. With these funds, we can create coalitions between the UIHPs and Marketplace and Medicare/Medicaid purchasers, both private and public. These coalitions can create a system that understands that our population is in immediate need of specialty care to stabilize chronic conditions, which will lead to primary care use for preventative medicine purposes. With a push towards capitation for public health purchasing, this type of dialog is essential to eliminate health disparities in our urban AI/AN population instead of sustaining a chronic state of health.

It is unfortunate that the urban AI/AN population finds itself suffering from almost constant disparity. Many factors have led us here: lack of representation (no urban voice in HHS Secretary's Tribal Advisory Committee or the OMH's AI/AN Health Research Advisory Council; lack of a single federal definition of AI/AN (five different definitions of AI/AN used in IHCA)<sup>10</sup>; a general acceptance of the federal government that conferring with and allocating almost entirely to tribes is addressing the health and human service needs of the entire AI/AN population, etc. We know that the AI/AN population is overrepresented in urban areas, yet severely lacks access to the federal trust. An AI/AN does not cease to be AI/AN just because they have left tribal lands. By geographically limiting the reach of the federal trust only to those AI/ANs who reside on tribal lands, we are forcing AI/ANs to think they cannot keep their identity by leaving the geographical boundaries of their tribe. Congress has acknowledged that the federal trust obligation does not end at the reservation boundary<sup>11</sup>. We need to follow the lead of the 1921 Snyder Act, which gives Congress broad discretion in allocating funds for the "care, benefit, and assistance of Indians throughout the United States."<sup>12</sup> That there is no tribal or geographical caveat in this legislation proves that the government does indeed have an obligation to all AI/AN people, regardless of where they choose to live.

By dedicating funds to address our data needs, understanding our healthcare access and utilization patterns, stabilizing our chronic conditions to lead to preventative care utilization, and addressing the emergent health and social threats, HHS can demonstrate that they are dedicated to ending the health disparities our AI/AN population faces. I want to be very explicit that in no way am I advocating for taking money from the tribes to fund these urban initiatives, as they are woefully underfunded as it is. I am asking that the Subcommittee increase their investment in Indian Country to a level that reflects actual need, thereby fulfilling the federal trust obligation the federal government has to our AI/AN population.

<sup>1</sup> U.S. Department of Commerce, Bureau of the Census. 1970 Census of Population: Subject Report – American Indians.

<sup>2</sup> U.S. Census Bureau. 2010. "Census 2010 American Indian and Alaska Native Summary File; Table: PCT2; Urban and rural; Universe Total Population; Population group name: American Indian and Alaska Native alone or in combination with one or more other races."

<sup>3</sup> U.S. Department of Health and Human Services. 2016. Justification of Estimates for Appropriations Committees, Indian Health Service Fiscal Year 2016. pgs. CJ-23, CJ-27.

<sup>4</sup> Urban Indian Health Institute, Seattle Indian Health Board. (2011) Community Health Profile: National Aggregate of Urban Indian Health Organization Service Areas. Seattle, WA: Urban Indian Health Institute.

<sup>5</sup> Subchapter IV of Chapter 18 of Title 25 of the United States Code (25 U.S.C. §§ 1651 et seq.).

<sup>6</sup> Castor ML, Smyser MS, Taulii M, Park A, Lawson SA, Forquera R. (2006). A nationwide population-based study identifying health disparities between American Indians/Alaska Natives and the general populations living in select urban counties. American Journal of Public Health, 96(8), 1478-84.

<sup>7</sup> The Urban Indian Health Institute. About Urban Indian Health Organizations.2015.

<http://www.uihi.org/about-urban-indian-health-organizations/>

<sup>8</sup> Testimony of Donna Keeler, President of the National Council of Urban Indian Health to the U.S. House of Representatives Appropriations Subcommittee on Interior, Environment, and Related Agencies Native American Witness Day Hearing, March 25, 2015.

<http://docs.house.gov/meetings/AP/AP06/20150325/102900/HHRG-114-AP06-Wstate-KeelerD-20150325.pdf>

<sup>9</sup> United States Census, 2010. 2010 Demographic Profile Data, King County, Washington.

<http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

<sup>10</sup> National Indian Health Board. The Definition of "Indian" Under the Affordable Care Act Approved by the Tribal Technical Advisory Workgroup. 2010.

<sup>11</sup> Senate Report 100-508, Indian Health Care Improvement Act Amendments of 1987, September 14, 1988, page 25.

<sup>12</sup> 25 U.S.C. §13,1921





# FIRST FOCUS

**First Focus  
Bruce Lesley, President  
Statement for the Record**

**House Committee On Appropriations Subcommittee On Labor, Health, and  
Human Services, Education And Related Agencies**

**Public Witnesses Hearing**

**April 29, 2015**

Chairman Cole, Ranking Member DeLauro, and Members of the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, thank you for the opportunity to submit this statement for the record which respectfully requests \$1,000,000 for a National Academy of Sciences study on reducing child poverty.

First Focus is a bipartisan children's advocacy organization dedicated to making children and families a priority in federal policy and budget decisions. Our organization is committed to ensuring that all of our nation's children have equal opportunity to reach their full potential.

Child poverty in the U.S. remains high, with 14.7 million or 19.9 percent of children living below the poverty line in 2013, and the child poverty rate remains significantly higher than for other age groups. Furthermore, poverty is a particularly serious problem for children, who suffer negative effects for the rest of their lives after living in poverty for even a short time.

Beyond consequences for individual children, child poverty negatively affects the entire nation through increased expenditures on criminal justice and healthcare and through lost revenue and economic output.

Yet in the US there remains a lack of awareness and government accountability to address the significant problem of child poverty, and proposed solutions are too often politicized and fall along partisan lines.

In order to make significant process in reducing child poverty in the US, we first need to achieve a broader awareness and consensus among lawmakers about the causes, costs to society, and negative outcomes associated with child poverty. We then need evidence-based, pragmatic solutions to address these causes.

Due to the National Academy of Sciences (NAS)'s long history of addressing difficult social policy questions in a balanced, judicious, and non-partisan manner, we propose that the Committee requests a NAS study on child poverty study. Such a study would provide an evidence-based, non-partisan analysis of child poverty in the U.S., including the macroeconomic costs, the health costs, the crime and other social costs, and direct federal budget effects of child poverty, as well as recommendations with the goal of reducing child poverty by half in 10 years.

This would not be a new item in the appropriations bill. The FY 15 Senate Labor-HHS Committee Report language included a request for this study on p. 155 that read "The Committee recommendation includes \$1,000,000 for the Secretary to enter into an agreement with the National Academy of Sciences to study current efforts aimed at reducing child poverty and propose recommendations with the goal of reducing child poverty by half in 10 years."

Therefore, we suggest the following committee language for FY16: "The Committee directs

\$1,000,000 for the Secretary to enter into an agreement with the National Academy of Sciences to conduct a study and make recommendations on reducing the number of children living in poverty in America by half in ten years. The study shall include information describing the macroeconomic costs, the health costs, the crime and other social costs, and direct federal budget effects of child poverty. Recommendations shall address improving the effectiveness and outcomes of poverty-related programs and services, improving the measure of poverty, eliminating disparate rates of poverty, expanding eligibility to improve the coordination of service delivery to low income children and improving the access of low income and unemployed individuals to good jobs. Consistent with past practice, the Committee expects the study to address non-partisan, evidenced-based approaches to child poverty that will both raise awareness and increase accountability for this urgent problem; the study will be delivered to the Committees of jurisdiction 1 year after the date of enactment of this Act.”

We greatly appreciate the leadership of Chairman Cole and Ranking Member DeLauro and look forward to working with you on this and other proposals to improve the well-being of America’s children.



AMERICAN ACADEMY OF  
FAMILY PHYSICIANS  
STRONG MEDICINE FOR AMERICA

## **Testimony to the House Subcommittee on Labor, Health and Human Services, & Education, and Related Agencies Appropriations FY 2016**

**April 27, 2015**

The American Academy of Family Physicians (AAFP), which represents 115,900 family physicians and medical students across the country, is pleased to submit this statement for the record urging the Committee to invest in our nation's primary care physician workforce in the fiscal year 2016 appropriations bill to promote the efficient, effective delivery of health care by providing these appropriations for the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ):

- \$71 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the *Public Health Service Act* (PHSA);
- \$4 million for Rural Physician Training Grants (PHSA Title VII, §749B);
- \$287 million for the National Health Service Corps (PHSA § 338A, B, & I); and
- \$375 million for the AHRQ (PHSA § 487(d)(3), SSA §1142).

Founded in 1947, the AAFP is dedicated to preserving and promoting the science and art of family medicine and ensuring high-quality, cost-effective health care for patients of all ages. The AAFP appreciates the opportunity to comment on the FY 2016 appropriations levels needed to achieve those important goals.

### **HRSA – Title VII Primary Care Training & Enhancement**

Our nation faces a shortage of primary care physicians which may worsen as care delivery models shift toward smaller ratios of population to primary care physicians.<sup>1</sup> HRSA is the federal agency charged

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with administering the health professions training programs authorized under Title VII of the *Public Health Services Act* and first enacted in 1963.

Family medicine relies on grants from the Primary Care Training & Enhancement (PCTE) program, authorized by Title VII, §747 of the *Public Health Service Act*, to support primary care training and the professional development of primary care faculty. PCTE is both effective and essential to support the family physicians workforce. A recent study of the effect of the PCTE funding opportunity announcement addressing faculty development needs found that targeted federal funding can bring about changes that contribute to an up-to-date, responsive primary care workforce.<sup>2</sup>

In addition to faculty development, the PCTE program allows grantees to test educational innovations, respond to changing delivery systems and models of care, and improve interprofessional education and training. The Advisory Committee on Training in Primary Care Medicine and Dentistry addressed the importance of learning in integrated systems of care supported by the PCTE program in their report to the Secretary of the U.S. Department of Health and Human Services and Congress released in December 2014. The report highlights the need to “integrate principles of interprofessional education with the building of community-based collaborations and partnerships in primary care practice.” Noting that current appropriations levels are inadequate, the report recommends that Congress provide “\$123 million to Title VII, Part C, sections 747 and 748 for FY 2016, restoring funding to inflation-adjusted FY 2003 levels.”<sup>3</sup>

**Recognizing the fiscal constraints on the FY 2016 appropriations, the AAFP urges that the Committee provide \$71 million for HRSA's PCTE program.**

**HRSA – Title VII Rural Physician Training Grants**

Another important HRSA Title VII grant program is the Rural Physician Training Grants program to help medical schools to recruit students most likely to practice medicine in rural communities. This modest program authorized by Title VII, §749B will help provide rural-focused training and experience and

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increase the number of recent medical school graduates who practice in underserved rural communities. Medical school rural programs (RPs) have been found to have a significant impact on rural family physician supply.<sup>4</sup> This program will help provide rural-focused experience and increase the number of medical school graduates who practice in underserved rural communities. An appropriation of \$4 million will support 10 grantees which will train a minimum of 100 students.

**The AAFP asks that the Committee provide \$4 million for the Rural Physician Training Grants Program as requested in the Administration's FY 2016 budget.**

**HRSA – National Health Service Corps**

Since in 1972, the National Health Service Corps, also administered by HRSA, has offered financial assistance to recruit and retain health care providers to meet the workforce needs of communities across the nation designated as health professional shortage areas. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of additional primary care physicians, and we support the Administration's budget request for the NHSC of \$287 million in discretionary appropriations as part of the FY 2016 spending bill.

The Government Accountability Office (GAO-01-1042T) described the NHSC as "one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas." As the only medical society devoted solely to primary care, the AAFP recognizes the importance of the NHSC to the reducing our nation's serious geographic disparities in health care access.

Not only does the NHSC program of placing physicians and medical professionals in health professional shortage areas to meet the needs of patients in rural and medically underserved areas, it also provides scholarships as incentives for medical students to enter primary care and to provide health care to underserved Americans. By addressing medical school debt burdens, NHSC scholarships ensure wider access to medical education opportunities by providing financial support for

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tuition and other education expenses, and a monthly living stipend for medical students committed to providing primary care in underserved communities of greatest need.

More than 40,000 providers have served in the NHSC since its inception. In FY 2014, the NHSC had a field strength of 9,242 primary care clinicians. NHSC physicians and health care providers were placed in HPSAs serving patients in every state and territory. However, the need for this important program currently exceeds the available investment.

**The AAFP recommends that Committee provide at least the requested appropriation of \$287 million for the National Health Service Corps for FY 2016.**

**HRSA – Health Centers**

HRSA's Health Center program continues to provide affordable comprehensive primary care services in medically underserved communities across the nation. The AAFP has worked closely with HRSA to promote data-driven community health center expansion. The mapping tool developed and managed by AAFP identifies areas in greatest need for Federally Qualified Health Centers. Since the launch of the tool on July 1, 2010, the UDS Mapper has registered over 4,500 users and can be found at <http://www.udsmapper.org/about.cfm>.

**The AAFP recommends that the Committee provides \$7.48 billion in discretionary funds for HRSA overall in the FY 2016 appropriations bill.**

**AHRQ – Primary Care Research**

The Agency for Healthcare Research and Quality (AHRQ) is the sole federal agency charged with producing evidence to support clinical decision-making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access. AHRQ supports important investigation in areas which are not the focus of investigation anywhere else in the biomedical research community. Evidence-based family medicine practice requires AHRQ-supported primary care research in areas such as Practice-Based Research Networks (PBRNs), practice transformation, patient quality and

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safety in non-hospital settings, multi-morbidity research, as well as the delivery of mental and behavioral health services in communities by primary care practices. Also important to successful primary care research is AHRQ's support future primary care investigators. We believe there is a need to deliberately promote this training as a way to aid in the development of all the areas we have emphasized. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded.

Primary care research includes: translating science into the active practice of medicine and caring for patients, understanding how to better organize health care to meet patient and population needs, evaluating innovations to deliver the best health care to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

The AAFP relies on research developed by AHRQ to answer key clinical questions based on AHRQ's Effective Health Care Program to help clinicians make better treatment choices. AHRQ helps to provide the critical evidence reviews needed to answer questions on the common acute, chronic, and comorbid conditions that family physicians see on a daily basis.

AHRQ research also examines health information technology inform meaningful use policy and practice so that health IT can be used more effectively to improve the quality of American health care.

**The AAFP requests that the Committee provide no less than \$375 million in appropriated funds for the Agency for Healthcare Research and Quality (AHRQ) to support research vital to primary care.**

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<sup>1</sup> Petterson, S, et al. Estimating the Residency Expansion Required to Avoid Projected Primary Care Physician Shortages by 2035. *Ann Fam Med* March/April 2015; vol.13 no. 2:107-114. <http://annfammed.org/content/13/2/107.full.pdf+html>

<sup>2</sup> Klink KA, Joice SE, McDevitt SK. Impact of the Affordable Care Act on Grant-Supported Primary Care Faculty Development. *Journal of Graduate Medical Education* Sep 2014, Vol. 6, No. 3 pp. 419-423

<sup>3</sup> Training Health Professionals in Community Settings during a Time of Transformation: Building and Learning in Integrated Systems of Care. Eleventh Annual Report to the Secretary of the US Department of Health and Human Services and to Congress. December 2014. <http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf>

<sup>4</sup> Rabinowitz, HK, et al. Medical School Rural Programs: A Comparison With International Medical Graduates in Addressing State-Level Rural Family Physician and Primary Care Supply. *Academic Medicine*, Vol. 87, No. 4/April 2012.





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THE VOICE OF BRAIN INJURY

## Testimony of the Brain Injury Association of America

Prepared for the Subcommittee on Labor, Health and Human Services,  
 Education and Related Agencies

On Administration for Community Living, CDC,  
 NIDILRR – Administration for Community Living

April 27, 2015

Chairman Cole and Ranking Member DeLauro, thank you for the opportunity to submit this written testimony with regard to the Fiscal Year (FY) 2016 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our network of state affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 2.5 million people sustain brain injuries from falls, car crashes, assaults, and contact sports. Males are more likely than females to sustain brain injuries. Children, teens, and seniors are at greatest risk. Currently, more than 5 million Americans live with a TBI-related disability.

Increasing numbers of service members returning from the conflicts in Iraq and Afghanistan with TBI and their families are seeking resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into their communities.

**Administration for Community Living** - BIAA respectfully urges you to relocate the Federal Traumatic Brain Injury (TBI) State Grant Program and Protection and Advocacy Systems Grant Program from the Maternal and Child Health Program of the Health Resources and Services Administration to the Administration for Community Living (ACL) in FY 2016 appropriations. The TBI Act Reauthorization, S. 2539, which was signed by President Obama on November 26, 2014, authorized appropriations for these critical TBI grant programs through 2019 and gave authority to the Secretary of the U.S. Department of Health and Human Services, with discretion on where to locate the TBI grant programs.

The TBI State Grant and Protection and Advocacy Grant Programs are designed to increase access to treatment and community-based services for individuals who are injured, protect the rights of those individuals, and to improve service system coordination within states and territories. Because people of all ages sustain TBIs and because the injury can negatively impact health and function across the lifespan, we believe it is in the best interests of individuals and families to move the TBI State Grant and Protection and Advocacy Systems Grant Programs to ACL.

As you know, several disability programs formerly housed in the U.S. Department of Education will move to ACL by July 2015 as a result of the Workforce Innovation and Opportunity Act of 2014. These programs include: the TBI Model Systems, the Research and Training Center on TBI Community Reintegration, the Independent Living Center program, and the Assistive Technology programs. Locating the TBI State Grant and Protection and Advocacy Grant Programs would only further enhance the existing collaboration and coordination among them. In addition, we believe placing the TBI State Grant and P&A Grant programs within ACL would help to:

- 1) integrate TBI into the HHS community long-term services initiatives, including the single point of entry through Aging and Disability Resource Centers;
- 2) promote collaboration with Administration on Aging (AoA) on falls-related TBIs among older adults and the lifespan respite care program;
- 3) include TBI in the veterans initiatives between HHS and Department of Veterans Affairs to support Home and Community-Based Services (HCBS) for veterans and returning service members; and
- 4) coordinate/enhance services for individuals with TBI who may also be eligible for services provided through State Intellectual/Developmental Disabilities systems and/or could benefit from Administration on Intellectual/Developmental Disabilities (AIDD) initiatives to improve education, employment outcomes, voting and self-advocacy.

**CDC – National Injury Center - \$10 million** (+ \$5 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness.

The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. The TBI Act as amended in 2014 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds states for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and \$1 million of this request would go to fund CDC's work in this area.

In the President's FY 2016 budget, a \$5 million increase was included for the Centers for Disease Control and Prevention (CDC) Injury Prevention and Control Center to develop sports

concussion surveillance to accurately determine the incidence of sports related concussions among youth ages 5-21.

**NIDILRR TBI Model Systems of Care** - Funding for the TBI Model Systems in the Administration on Community Living is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should increase funding in FY2016 for NIDILRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDILRR budget. Specifically, the Congressional Brain Injury Task Force requests increased funding by \$13 million over the next six years to support the TBI Model Systems program:

- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed; when re-competed, increase from \$625,000 to \$1 million annually;
- Increase funding for centers by \$150,000 annually from the current average of \$437,500;
- Increase the number of competitively funded centers from 16 to 18; and
- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to five, each with an annual budget of \$1.5 million (current funding is \$600,000 each).

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist states in coordinating services, protect the rights of persons with TBI, and bolster vital research.



**Testimony Prepared by Laurie Lang, Executive Director of Project Angel Food for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Food is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 520,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

### **1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a

critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

## **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

## **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.

- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

## **Conclusion**

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.



Thank you.



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<sup>14</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013, Boston, MA. Abstract #: 290277

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**Centers for Disease Control and Prevention (CDC) Coalition**

C/o American Public Health Association 800 I Street NW Washington, DC, 20001 202-777-2514

Donald Hoppert, Director of Government Relations, American Public Health Association  
 Testimony submitted for the record on April 27, 2015  
 House Appropriations Subcommittee on Labor,  
 Health and Human Services, Education and Related Agencies

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just the individual programs that it funds and urge a funding level of **\$7.8 billion for CDC's programs in FY 2016**. We are pleased President Obama's FY 2016 budget request would increase CDC's program level by \$141 million over FY 2015. The president's budget provides additional funding for several important new and existing programs and initiatives such as combating antibiotic resistance and preventing prescription drug overdose. We are also pleased that the president's budget would fully allocation the Prevention and Public Health Fund for public health activities. Unfortunately, the president's budget also cuts or completely eliminates other important programs such as the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations, environmental health tracking and others and we urge you to restore this funding.

CDC is a key source of funding and technical assistance for state and local programs that aim to improve the health of communities. CDC funding provides the foundation for state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the prevention and control of Ebola

in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating the ongoing multi-state measles outbreak to pandemic flu preparedness, CDC is the nation's – and the world's – expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC's infectious disease, laboratory and emergency preparedness and response activities.

Heart disease is the nation's No. 1 killer. In 2013, over 611,000 people in the U.S. died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More males than females died of heart disease in 2013, while more females than males died of stroke that year. Stroke is the fifth leading cause of death and is a leading cause of disability. In 2013, nearly 129,000 people died of stroke, accounting for about one of every 20 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health.

Cancer is the second most common cause of death in the U.S. More than 1.6 million new cancer cases and 589,430 deaths from cancer are expected in 2015. In 2011 the direct medical costs of cancer were \$88.7 billion. The National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to all 50 states to develop comprehensive cancer control plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and

implement specific cancer prevention and control activities customized to address each state's particular needs.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign that help to prevent tobacco addiction and provide resources to encourage smokers to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the 29.1 million Americans who have diabetes, more than 8 million cases are undiagnosed. In 2012, about 1.7 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were \$245 billion in 2012. The Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. While the obesity rates among children between the ages of 2-5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity.

Arthritis is the most common cause of disability in the U.S., striking more than 52 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, 21 percent of who are undiagnosed. The number of people living with HIV is increasing as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic.

Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system almost \$16 billion annually.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey are an essential part of the nation's statistical and public health infrastructure and must be adequately funded.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, \$10.20 is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths

are prevented each year through timely immunization. We urge you to restore the president's proposed cuts to the Section 317 Immunization program.

Injuries are the leading causes of death for people ages 1-44. Unintentional injuries and violence, such as older adult falls, prescription drug overdose, child maltreatment and sexual violence, account for approximately 31 percent of emergency department visits each year. Annually, injury and violence cost the U.S. approximately \$406 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control works to prevent injuries and minimize their consequences.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects who survive often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and it is estimated that up to 57 million people in the U.S currently live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts important programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders

The National Center for Environmental Health works to protect public health by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support adequate funding for NCEH. We urge you to support the president's request for increased funding for the Climate and Health Program and to restore the proposed cuts to the Environmental and Health Outcome Tracking Network.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our **FY 2016 request of \$7.8 billion for CDC's programs.**



AMERICAN PUBLIC HEALTH ASSOCIATION

*For science. For action. For health.*

Georges C. Benjamin, MD, Executive Director, American Public Health Association  
 Testimony submitted for the record on April 27, 2015  
 House Subcommittee on Labor, Health and Human Services, and Education, and Related  
 Agencies

APHA is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at \$7.8 billion and the Health Resources and Services Administration at \$7.48 billion in FY 2016. However, we are concerned that the House Labor-HHS allocation would make it nearly impossible to adequately fund these important public health agencies.

**Centers for Disease Control and Prevention:** We believe Congress should support CDC as an agency, not just the individual programs that it funds. We are pleased President Obama's FY 2016 budget request would increase CDC's program level by \$141 million over FY 2015. The president's budget provides additional funding for several important new and existing programs and initiatives such as combating antibiotic resistance and preventing prescription drug overdose. We are also pleased that the president's budget would fully allocation the Prevention and Public Health Fund for public health activities. Unfortunately, the president's budget also cuts or completely eliminates other important programs such as the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations, environmental health tracking and others and we urge you to restore this funding.

CDC is a critical source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more

than 70 percent of CDC's budget supports public health and prevention activities by state and local health organizations and agencies, national public health partners and academic institutions. CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for state and local capacity grants. Unfortunately, this is not a threat that is going away.

CDC serves as the command center for the nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the prevention and control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating the ongoing multi-state measles outbreak to pandemic flu preparedness, CDC is the nation's — and the world's — expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address chronic diseases such as heart disease, stroke, cancer, diabetes and arthritis that continue to be the leading causes of death and disability in the United States. These diseases, many of which are preventable, are also among the most costly to our health system. The center provides critical funding for state programs to prevent chronic disease, conducts surveillance to collect data on disease prevalence, monitors intervention efforts and translates scientific findings into public health practice in our communities.



The National Center for Environmental Health works to protect public health by helping to control asthma, protecting our communities from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. We ask you to support adequate funding for NCEH and to support the president's request for increased funding for the Climate and Health Program and to restore the proposed cuts to the Environmental and Health Outcome Tracking Network.

Prescription drug overdose is an ongoing public health problem in the U.S. killing more than 145,000 over the past decade. We urge you to support the president's request for increased funding that would allow all 50 states to participate in the PDO Prevention for States program to undertake efforts to prevent and reduce prescription drug and heroin overdose deaths.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to support the president's request for the CDC Antibiotic Resistance Initiative which would build prevention programs in all 50 states and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria.

**Health Resources and Services Administration:** HRSA operates programs in every state and U.S. territory and has a strong history in improving the health of Americans through the delivery of quality health services and supporting a well-prepared workforce of sufficient size. The agency serves the health needs of people who are medically underserved, low-income and geographically isolated. The nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. We are deeply concerned that since FY 2010, HRSA's discretionary budget

authority has been cut by 18 percent. Funding for HRSA is far too low to address the present health needs of the U.S. and will threaten the agency's ability to adequately respond to the growing and changing health demands.

HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health. HIV/AIDS programs administered by HRSA provide access to regular care and ensure adherence to antiretroviral treatment for people living with HIV, which reduces HIV transmission by 96 percent and greatly contributes to the prevention of new HIV infections. The Title X Family Planning Program has greatly contributed to decreasing unintended pregnancy – helping to prevent an estimated 870,000 unintended pregnancies in 2013.

A committed investment from Congress in critical HRSA programs is required to continue achieving these health improvements and pave the way for new achievements, including:

Health Workforce supports the education and training of a broad range of health professionals.

With a focus on primary care and training in interdisciplinary, community-based settings, these are the only federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce. The programs are responsive to the changing delivery systems, models of care and health care needs, and encourage collaboration between disciplines to provide coordinated care that is effective and efficient.

Primary Care more than 9,000 health center sites in every state and U.S. territory, improving access to care for more than 21 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.

Maternal and Child Health including Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities,

combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 42 million women and children, including children with special health care needs.

HIV/AIDS provides assistance to states and communities most severely affected by HIV/AIDS.

The programs deliver comprehensive care, prescription drug assistance and support services for about half of the total population – 1.2 million people – living with HIV/AIDS in the U.S.

Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

Family Planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for more than 4.5 million low-income women, men and adolescents. This program helps improve maternal and child health outcomes, promotes healthy families and reduce unintended pregnancies, infertility and related morbidity.

Rural Health improves access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of health care services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than one percent of federal spending. Cuts to public health and prevention programs will not balance our budget and will only lead to increased costs to our health care system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone so that we can meet the mounting health challenges facing our nation.

**John May, M.D., Deputy Director, Northeast Center for Occupational Health and Safety**

**Association of University Programs in Occupational Health and Safety (AUPOHS)**

On behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the ten Agricultural Centers for Disease and Injury Research, Education, and Prevention funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the Fiscal Year 2016 Labor, Health and Human Services Appropriations bill include level funding of \$27.5 million for the Education and Research Centers and \$24 million for the Agriculture, Forestry and Fishing (AFF) Program within the NIOSH budget.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each year more than 3 million workers are seriously injured on the job, daily, 12 workers die from an injury suffered at work, and 145 workers die from work-related diseases, costing the industry and citizens an estimated \$4.8 billion per week. This is an especially tragic because work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs.

NIOSH is the federal agency responsible for supporting education, training, and research for the prevention of work-related injuries and illnesses in the United States. Some programs focus upon the most dangerous occupations in the US. Another NIOSH program aims to provide training to current health professionals while educating the next generation of professionals. These Education and Research Centers (ERCs) are regional and national resources for parties involved with occupational health and safety – industry, labor, government, academia, and the

public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

- Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- Professional Training: ERCs support 86 graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.
- Research Training: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- Continuing Education: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 18 ERCs, as well as through distance learning technologies.
- Regional Outreach: Responding to specific requests from employers, health care professionals, and workers on issues related to occupational health and safety.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72% to over 31 million. Work related injury and fatality rates increase at age 45, with rates for workers 65 years and older nearly three times greater than younger workers. In addition to changing demographics, the rapid development of new technologies poses many unanswered questions

with regard to workplace health and safety that require urgent attention. Newly emerging risks, such as Ebola and other infectious disease outbreaks, require swift responses to the need for worker protection.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety. The ERCs play a crucial role in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses. For example, NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers. In addition, in response to risks posed by potential Ebola exposure, ERCs have delivered educational programs and provided expertise in developing protocols and policies to prevent worker exposure. Additionally, NIOSH is the federal agency that is charged with certifying and approving the respirators that are required to protect U.S. workers. We need manpower to address these challenges and it is the ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life.

NIOSH also focuses upon the nation's most dangerous work. People who work in agriculture, forestry and fishing experience occupational fatality rates that are 6 times to more than 30 times higher than the average for American workers. The Agricultural Safety and Health

Centers program was established by Congress in 1990 (P.L. 101-517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes nine regional Centers for Agricultural Disease and Injury Research, Education, and Prevention and one national center to address children's farm safety and health. The AFF program is the only substantive federal effort to meet the obligation to ensure safe working conditions for workers in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S., most AFF operations are themselves small: nearly 78% employ fewer than 10 workers, and most rely on family members and/or immigrants, part-time, contract and seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms. In 2012 the AFF sector had a work-related fatality rate of 22 per 100,000 workers, the highest of any sector in the nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on the most dangerous farms – those with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings.

NIOSH Agricultural Center activities include:

- AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99% of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 140 close calls with no injuries among farmers who had installed ROPS. 99% of program participants said they

would recommend the program to other farmers. Similar programs are now offered to prevent serious injuries due to entanglement in other farm machinery.

- Working in partnership with producers and farm owners, the NIOSH AFF Centers have developed evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing had a reported annual fatality rate 58 times higher than the rate for all U.S. workers in 2009. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. A NIOSH AFF-funded team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the US Coast Guard's revision of regulations requiring commercial fishing vessel captains complete navigation training.
- The Centers have partnered with producers, employers, the federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and health care providers about the best way to treat *and* prevent agricultural injury and illness.
- New tools and work processes have been introduced and widely adopted by agricultural producers because they reduce musculoskeletal injury and pain and at the same time improve productivity.
- In 2010, the logging industry had a reported fatality rate of 91.9 deaths per 100,000 workers (preliminary data), a rate more than 25 times higher than that of all US workers. NIOSH AFF Centers, including the Southeast and the Northwest, are uniquely positioned to ensure the safety of our nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and wellbeing of others in our communities.



**William L. Dewey, Ph.D., President,  
Friends of the National Institute on Drug Abuse**

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding their causes through the research agenda of the National Institute on Drug Abuse (NIDA). Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

***Marijuana Research.*** *The committee recognizes that many states either have or are considering legalizing or making marijuana available for medical use without appropriate knowledge about its effects on human development, structure and function of their brains. Therefore the committee supports the Adolescent Behavioral Cognitive Development (ABCD) Study being initiated by NIDA and other institutes of NIH. The committee also recognizes that the study will take at least a decade to complete since it will be a comprehensive study of the effects of marijuana and other abused drugs throughout growth from 10 to 20 years of age. Further the*

*committee recognizes the cost of this comprehensive study should not inhibit funding investigator initiated studies and a special appropriation for this study is necessary.*

***Opiate Abuse and Addiction.*** *The Committee is concerned about the escalating crisis of prescription drug abuse in the U.S. It is now estimated that 120 people die each day in this country from opioid overdose making it one of the highest causes of non-disease related causes of deaths for adolescents and young adults. The June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the nation of \$72,500,000,000. Further, the Committee is very concerned with the concomitant rise in heroin abuse, addiction and deaths as the cost of this illegal opioid is less than that for prescription opioids. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research to enhance the development of such medications; and 3) report on what we know regarding the transition from prescription opiate analgesics to heroin abuse and addiction within affected populations.*

***Medications Development.*** *The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that decrease the ability of specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations to affect the brain. The Committee is excited by this approach - if successful, immunotherapies, alone or in*

*combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.*

***Research to Assist Military Personnel, Veterans, and Their Families.*** *The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.*

***Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.*** *The Committee is pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other health care professionals to increase especially those treating our youth to better recognize the signs that lead to drug abuse and addiction. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.*

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity

and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease –this new knowledge has helped to correctly emphasize the fact that drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends – significant declines in a wide array of youth drug use -- over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalties due to heroine, as well as the continued abuse of prescription

opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the FY2016 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15-44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

**William L. Dewey, Ph.D.**  
**Professor and Chair**  
**Virginia Commonwealth University Department of Pharmacology and Toxicology**  
**The College on Problems of Drug Dependence**

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the research supported by the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group of scholars in the United States addressing problems of drug dependence and abuse. The organization serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. CPDD also works in collaboration with the World Health Organization. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

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Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

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**Person Submitting Testimony:** Lois V. Simpson, Executive Director

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of The Advocacy Center (AC), the Protection and Advocacy (P&A) agency for Louisiana on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, the Advocacy Center served 177 individual clients, held 22 trainings with 2,148 people trained, and provided informational and referral services to an additional 469 people. In addition to these activities, 30,019 people were impacted by the activities undertaken by the Advocacy Center on behalf of groups of clients. These activities benefited individuals in every state and territory in the United States.

As an example of the work done by the Advocacy Center concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

**EXAMPLE #1:** Client B.M. is a person with a developmental disability who lives independently and receives services through the New Opportunities (NOW) waiver. He contacted the Advocacy Center after a direct support worker (DSW) emptied his bank account, which included funds that he had been saving through Social Security's PASS program, and used his credit cards without his permission. The AC alerted the provider agency and the regional Human Services District, and ensured that the DSW was removed from B.M.'s home. Then the AC staff brought B.M. to the AC office for an emergency meeting with the provider agency regarding security at his home.

Next, the AC staff helped B.M. to contact his bank, the police and the Social Security Administration to file reports and to ensure that SSA would not penalize B.M. for withdrawing his PASS funds. AC staff conducted numerous meetings with B.M.'s waiver team to ensure that B.M. would be safe in his home and continue receiving his full services.

One of AC's attorneys filed and the court granted a temporary restraining order, permanent restraining order, and permanent injunction against the DSW on B.M.'s behalf.

After the provider attempted to terminate B.M.'s services, claiming that he had violated their policies, that same attorney successfully demanded that the provider withdraw the notice and continue services until a new provider could be hired. Staff then helped B.M. interview and hire a new provider and DSW. The AC attorney wrote demand letters to the original provider agency for the reimbursement of the full amount stolen by their employee, which was over \$2,000.00. The

provider agency has since refunded the full amount and, again, with AC help, B.M. has been able to resume saving PASS funds for a new van.

**EXAMPLE #2:** L.W. is a person with a developmental disability who lives independently and receives services through the NOW waiver. L.W.'s provider agency approached AC for help after L.W.'s SSI benefits were terminated due to a finding that he was no longer disabled. The AC Attorney interviewed the client, his family, his provider agency, and his job coaches to determine how best to appeal the denial of his benefits. She reviewed the Social Security file and medical records, as well as the stated reasons for the denial of the client's benefits, and consulted with our WIPA experts at length about the finer points of Social Security benefits and entitlements and how earned income may affect a client's benefits. The AC Attorney then represented L.W. at the hearing on his SSI denial. She examined witnesses who could speak to L.W.'s ongoing disability, his supportive work environment, and his need for support in his activities of daily living. She submitted a memorandum, medical records, and witness declarations to the Administrative Law Judge, who ordered additional medical and psychological evaluations.

After L.W. was re-evaluated, the court issued a "fully favorable judgment," finding that L.W. had always been disabled under the Social Security standards and that his benefits should never have been terminated. L.W.'s benefits resumed immediately, and he will receive back benefits for the long period during which he did not receive SSI.

**EXAMPLPLE #3** AC was successful in requiring the Recovery School District in New Orleans to change its policy as it relates to children with disabilities who were being expelled based on an incidents not

related to the children's disabilities. Prior to the AC's advocacy, a Hearing Officer with the Recovery School District would order these children with disabilities to be placed at the alternative school. Such placement by a Hearing Officer violates both State and Federal Law. The law requires that the student's IEP Team, not the school district, must select the setting to which the student will be removed regardless of the reason for the removal of a student with a disability. AC contacted the school district and advised the district that it was violating State and Federal law. The district immediately contacted the Louisiana Department of Education. AC attorneys then had a discussion of this matter with Louisiana Department of Education's Office of Legal Services. The Louisiana Department of Education confirmed that in compliance with Federal and State Law, the Recovery School District will now refer all students with disabilities who are expelled for an incident found not related to their disability back to an IEP team and the team will determine placement of the student. As a result AC's advocacy and the change in the Recovery School District's policy, the rights of children with a disabilities facing expulsion based on an incidents not related their disabilities are now protected.

**EXAMPLE #4:** The grandmother of an 18-year-old young man with a developmental disability contacted AC because her grandson had impacted wisdom teeth, which his oral surgeon recommended extracting. The client had received a denial on two of the four teeth, for no apparent reason. The oral surgeon's office told them that Medicaid had recently been denying these claims on "everybody."

Because the young man was a Chisholm class member (a case the AC filed back in 2000), and the notice of denial showed that procedural requirements of Chisholm regarding prior authorization denials had not been followed, AC's attorney wrote the LA. Department of Health and Hospitals

about the case, asking for immediate attention to our client's situation and information on all Chisholm class members who had had their dental claims denied by the contractor in question.

Almost immediately, the services for the client were approved. The attorney then received a letter from DHH Legal with information on 66 other Chisholm class members who have had dental prior authorization claims denied by the same contractor. These claims are going to be reviewed to resolve any unnecessary bureaucratic barriers to approval (for example, our client's notice said that they had not received enough documentation from the dentist). The clients will get new Chisholm-compliant notices if the claims are going to be denied. We will have a chance to try to contact all 66 to make sure they get the services they need.

Thank you for this opportunity to submit this testimony.

Written testimony to the House of Representatives April 2015. Carla Javits, President and CEO of REDF ([www.redf.org](http://www.redf.org)) ([cjavits@redf.org](mailto:cjavits@redf.org))

## Testimony

The Social Innovation Fund (SIF), administered by the Corporation for National and Community Service, has played a vital role in creating jobs and the opportunity to work, and has delivered new evidence that demonstrates what is most effective in employing people who face significant barriers. The result of the government's SIF investment in REDF, as documented by a recent evaluation completed by Mathematica Policy Research, is significant taxpayer savings—\$13,250 in reduced taxpayer burden per social enterprise employee. On average, the people who are employed receive 33% less income from public benefits, and 481% more from work. They increase their wage and salary incomes by 268%, and the percent of those in stable housing more than tripled. Final results of an evaluation conducted by MDRC of the Center for Employment Opportunities' social enterprise as part of the federally funded Enhanced Services for the Hard-to-Employ Demonstration and Evaluation Project, shows social enterprise can also significantly reduce recidivism with the largest impacts for the group of participants recently released from prison. This group was significantly less likely than control group members to be arrested, convicted of a crime, or incarcerated. These impacts represent a reduction in recidivism of 16 percent to 22 percent across the three outcomes.

We strongly urge the Committee to approve a new appropriation for the Social Innovation Fund in FY 2016 as it produces results for taxpayers and communities, and builds the evidence base about what works in solving some of our most intractable problems.



Written testimony to the House of Representatives April 2015. Carla Javits, President and CEO of REDF ([www.redf.org](http://www.redf.org)) ([cjavits@redf.org](mailto:cjavits@redf.org))

Millions of people in the US are unemployed for the long-term, despite the fact that they want to work, and even in the context of an economy that is back to creating hundreds of thousands of jobs with falling rates of unemployment. They find it difficult to obtain employment because long gaps in their work history, histories of incarceration, and lack of basic work skills make employers reluctant to hire them.

When people do not work, we fail to leverage all of the talent available to our country. We all pay the price of diminished economic contributions, weakened ties to family and civic life, higher costs of safety net programs, and recidivism to incarceration and homelessness. Families lose out when parents or guardians are not working, because they and their children are disconnected from networks of support, and economic and social mobility.

Everyone who wants to and can work should have a job with the chance to bring their skills and talents to bear, to be part of a team, to contribute, to be included as a full member of the community, with reasonable pay, and the opportunity for upward mobility.

Social enterprises leverage a business approach to address a social mission; and REDF supports these mission-driven businesses that focus on hiring and assisting people who face barriers to work. They earn and reinvest their revenue to provide more people with jobs that build skills and a career path. They help people who are willing and able to work, but have the hardest time getting jobs. In doing so, they enable people to realize their full potential through a financially sustainable and cost-effective model. They operate with a double

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bottom line that makes this model sustainable, selling quality goods and services and generating earned revenue, which is reinvested into hiring more people.

For 18 years, California-based REDF has led the pioneering effort to launch and grow social enterprise businesses in California through a combination of financial and technical assistance, and access to networks, successfully adapting a venture capital approach to achieve social benefit. As a result, thousands of people have gone to work, and the social enterprises themselves have generated more than \$145 million in earned revenue, making this a sustainable and scalable model.

REDF was founded by Bay Area resident George R. Roberts, Co-Chairman of the global private equity firm KKR, who continues as Chairman of the REDF Board of Directors. He developed this results-oriented business model to address chronic joblessness.

REDF and the social enterprise model have been recognized and fueled by a five year investment of The Social Innovation Fund (SIF), which is administered by the federal Corporation for National and Community Services and supported by Congressional appropriations. The SIF is a champion of results-oriented, evidence-based public sector and social impact investing, and their grantees have leveraged hundreds of millions of dollars of private philanthropic support. As the only California-based intermediary funded by the SIF up until last year, when one additional California intermediary won the competition, REDF's portfolio of enterprises has also generated significant earned revenue as the mission-driven businesses in its portfolio have grown.

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While California has been a leader in social enterprise development, these enterprises are located in many other cities throughout the US and represent a wide array of different industries. REDF convenes and informs these enterprises about best practices, evaluation findings, and tools and resources that foster growth through its SE4Jobs Network, and a new on-line community [REDFworkshop.org](http://REDFworkshop.org).

Examples of social enterprises follow. Based in Los Angeles and Santa Monica, Chrysalis Enterprises has created transitional jobs for clients with the greatest barriers to employment. By providing valuable work experience, Chrysalis Enterprises helps clients gain the necessary skills needed to re-enter the job market. During a single year, Chrysalis employs 650 people and generates more than \$2 million in wages.

The Cara Program in Chicago, Illinois has placed over 3,250 people into quality, permanent employment, helping families to end the transfer of inter-generational poverty. The Cara Program has three social enterprises: Cleanslate, TCP Staffing and Chapter Two – achieving a double bottom line: more than \$2 million in annual revenue and 350 transitional jobs for the hardest to employ. Similar organizations across California and the United States -- from the path breaking San Francisco-based New Door Ventures' Ashbury Images and Pedal Revolution, to Sacramento's Crossroads Diversified Services, to Greyston Bakery in Yonkers, New York; RecycleForce in Indianapolis, Indiana, Reworx in Atlanta, Georgia, and the Women's Bean Project in Denver, Colorado -- create jobs in businesses that recycle electronic waste, bake brownies for Ben and Jerry's Ice

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Cream, make bean soup and jewelry, deliver property services, sell and refurbish bicycles, screen print shirts and other products, and clean the streets.

The stories of the success achieved by the employees are inspiring. A former Chrysalis employee went down the crooked path, as he put it, and spent almost 3 decades in prison. When he left prison, he decided he needed to turn his life around. He got a job as part of Chrysalis' street cleaning crew and through hard work moved up to front desk staff. He now manages his own building in Los Angeles and is paying for his daughter to go to college. "My family loves me. They appreciate me. They don't look at me as that bad guy anymore. Now when they see me coming, hands are extended."

By acting to accelerate the growth of these mission-driven businesses, the SIF is creating jobs and employment opportunities for people who face significant barriers to entering the workforce. By securing and retaining employment, these employees contribute their talents to the economy, pay taxes and participate in the community, foster the success of their children, and end their cycle through costly government programs and systems. Employers can access a pool of dedicated and hard-working talent for front line positions that can be difficult to fill with well-prepared workers. *Economic and social benefits flow to all of us when more people are working.*

There is both the opportunity and need to significantly expand this model. REDF is initiating a new campaign with leaders from around the country to grow these mission-driven businesses throughout the US and deepen their connections with mainstream employers.

**Person Submitting Testimony: Ann MacLaine, Executive Director, Disability Rights**

**Mississippi**

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)** (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of Disability Rights Mississippi (DRMS), the Protection and Advocacy (P&A) agency for Mississippi, on community integration and ensuring access to services for people with intellectual and developmental disabilities. DRMS receives approximately \$425,000 per year from the Administration on Intellectual and Developmental Disabilities (AIDD) for its protection and advocacy work under the Protection and Advocacy for Developmental Disabilities (PADD) program.

Since 1982, DRMS has been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning their education, employment, housing, and health care.

In 2014, Disability Rights Mississippi's PADD program represented 156 individual clients, trained an estimated 950 people, and provided informational and referral services to an additional 235 people. In addition to these activities, an estimated 51,506 people were impacted by the activities undertaken by Disability Rights Mississippi on

behalf of groups of clients. These activities benefited individuals throughout the State of Mississippi.

Below are some examples of our work on these topics:

- DRMS has positively influenced the public education of students with disabilities in Mississippi by filing numerous complaints over the past several years with the MS Department of Education against local school districts for failure to provide students with free, appropriate educations as required by federal law. In all cases, the state has validated the complaints, and ordered the districts to take corrective action. DRMS closely monitors implementation of these corrective actions. In one case, it filed suit against the MS Department of Education for failing to ensure that the district had fully corrected its deficiencies two years after being ordered to do so. That suit was settled in 2014, via an agreement for close monitoring by the state and regular reporting to DRMS. This case affects thousands of students with emotional and behavioral disabilities in the Jackson public school district. Appropriate educational services in the community keep families together and prevent children with developmental and intellectual disabilities from becoming warehoused or segregated from their families and communities.
- DRMS has assisted individuals in transitioning from facility to community settings through individual advocacy, monitoring of the state Medicaid agency's Bridge to Independence Program, and providing input to the state and the US Department of Justice (DOJ) in their attempts to negotiate a settlement of DOJ findings in December 2011 of state non compliance with the Americans with Disabilities Act's community integration mandate. In 2014, DRMS provided input to an

independent technical assistance entity with which the state has contracted to help it fashion recommendations in connection with those negotiations. While this process has not moved as quickly as anyone would like, many changes have been made and are being planned to ensure that a broad array of services and supports are available in community settings so that individuals have meaningful choices.

- DRMS regularly monitors facilities and programs which serve individuals with intellectual and developmental disabilities, and investigates allegations of abuse, neglect, or rights violations in facilities and in the community. It assisted a woman with intellectual disabilities to escape from an abusive home environment and obtain the services she desired in another state. It has challenged use of aversive techniques for behavior management resulting in the discontinuation of those methods.
- DRMS has continued its work to ensure that youth and young adults with intellectual and developmental disabilities have opportunities for integrated, competitive employment. This has been achieved by improving collaboration among advocates, schools, and adult service systems, and by urging state policymakers to make competitive employment for people with disabilities a priority. In 2014, an Executive Order establishing such a policy was issued by the Governor.
- In late 2014, DRMS began working to insure that recently issued rules for Medicaid home and community based services are followed within the State of Mississippi. This follows years of efforts, both for individuals and systemically, to ensure that individuals with disabilities in Mississippi received the Medicaid

services to which they are entitled by federal law. DRMS has successfully represented over 20 children who qualified for Medicaid's Disabled Child Living at Home program but who were denied or terminated from the program as a result of MS Medicaid's new interpretation of the federal rules. It has also persuaded Medicaid to change policies that categorically denied certain types of Assistive Technology to adults. Because receipt of medically necessary medical services is essential to successful community living, DRMS has continuously educated stakeholders about their rights to appeal and due process regarding Medicaid decisions.

In summary, Disability Rights Mississippi promotes and respects the choices of its clients. In the past, many people with intellectual and developmental disabilities have not been given meaningful choices in Mississippi because of limited options or lack of knowledge of their rights. DRMS works every day to empower people with disabilities to live full, productive lives of their own choosing.

Thank you for this opportunity to submit this testimony.



**Testimony**

**Susan Peschin, MHS, Chair, Friends of the National Institute on Aging (NIA) and  
President & CEO, Alliance for Aging Research  
House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services  
National Institutes of Health/National Institute on Aging  
April 27, 2015**

Chairman Cole, Ranking Member DeLauro, and members of the Committee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), [www.friendsofnia.org](http://www.friendsofnia.org), a coalition of more than 50 academic, patient-centered and non-profit organizations that supports the research and training missions of the National Institute on Aging (NIA). Considering the resources the federal government spends on the health care costs associated with age-related diseases, we feel it makes sound economic sense to increase federal resources for aging research. **Specifically, given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends an additional \$500 million in the FY 2016 National Institutes of Health (NIH) budget to support biomedical, behavioral, and social sciences aging research efforts at the NIH.** We believe that this funding is the minimum essential to sustain research needed to make progress in attacking the chronic diseases that are driving significant increases in our national healthcare costs. **In addition, to ensure that overall NIH research progress continues, the Coalition endorses the Ad Hoc Group for Medical Research in supporting at least \$32 billion for NIH in FY 2016.**

NIA's mission is urgent. The number of Americans aged 65 and older is growing at an unprecedented rate. By 2030, there will be 72 million Americans in this age group; more

than double the number from 2000. The number of “oldest old”—people age 85 or older—is expected to more than triple between 2010 and 2050. Age is a primary risk factor for many disabling diseases and conditions—most notably, Alzheimer’s disease (AD). The NIA is the primary federal agency responsible for AD research and receives nearly 70 percent of the NIH Alzheimer’s disease research funding. We know that as many as 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.2 million by 2050. NIA’s comprehensive AD research program spans the spectrum of discovery, from basic neuroscience through translational research and clinical application. The [National Alzheimer’s Plan](#), 2012 and 2015 Research Summits, and allocation of additional funds from the NIH Director in 2012 and 2013 have accelerated momentum in this field. In 2016, several exciting trials incorporating biomarkers of disease will be active). NIA will also continue to support treatment trials to slow the disease or alleviate its symptoms, such as the recent study in which NIA-supported researchers found that the anti-depressant citalopram may be a safer and more effective treatment for disruptive agitation in AD than the treatments currently in use. Efforts in AD research have been bolstered by the advent of new technologies to generate and analyze enormous data sets. These new technologies have been particularly effective in identifying risk and protective genes for AD. Researchers can now access the first batch of genome sequence data from the [Alzheimer’s Disease Sequencing Project](#) (ADSP), a collaboration between the NIA and the National Human Genome Research Institute to facilitate identification of risk and protective genes.

Because aging is the single biggest risk factor for the development of many chronic diseases, a better understanding of the basic biology of aging may open up new avenues for prevention and cures. The establishment of the trans-NIH GeroScience Interest Group (GSIG) to facilitate discovery on the common risks and mechanisms behind age-related diseases and conditions has invigorated the field of basic geroscience, as have groundbreaking recent findings such as the discovery that the protein GDF-11 can reverse aging-related cardiac hypertrophy (a dangerous thickening of the heart muscle) in mice—the first time a circulating factor has been shown to reverse age-related damage in a mammal. Recommendations from the 2013 GSIG Summit entitled “Advances in Geroscience: Impact on Healthspan and Chronic Disease” continue to energize researchers in this field.

NIA maintains an ongoing commitment to supporting basic behavioral and social research in aging. The NIA-supported Health and Retirement Study remains the world’s premier multidisciplinary source of data on the health and well-being of older Americans, linking objective and subjective measures of health with information about retirement, economic status, family structure, personality, as well as health behaviors and service utilization. Funds from ARRA facilitated expansion of the study, including genotyping DNA samples from participants. In FY 2016, research will be ongoing to take advantage of the newly available genetic data to advance understanding of how genetic, behavioral, and psychosocial factors affect health and well-being. NIA remains an active participant in the trans-NIH Science of Behavior Change initiative and the Basic Behavioral and Social Science Opportunity Network. NIA has also established an

initiative to elucidate why the United States lags behind most other industrialized countries in health at older ages and longevity.

The Institute continues to place a strong emphasis on translating scientific discovery into health. For example, researchers with the Lifestyle Interventions and Independence for Elders study found that a carefully structured, moderate physical activity program can reduce the risk of losing the ability to walk without assistance, perhaps the single most important factor in whether vulnerable older people can maintain their independence. This is the first specific intervention proven in a randomized trial to prevent mobility disability. Other NIA-supported investigators have recently proposed the first diagnostic criteria for age-related sarcopenia, a loss of muscle mass that is often associated with weakness and is a frequent contributor to frailty in older age. NIA is also partnering with the Patient-Centered Outcomes Research Institute on a major intervention study to prevent injurious falls, a key cause of disability in older people.

NIA also supports several innovative programs dedicated to training the next generation of aging researchers. The Advancing Diversity in Aging Research through Undergraduate Education Program, which supports creative and innovative undergraduate-level research education programs to diversify the workforce in aging; the Grants for Early Medical/Surgical Specialists Transition to Aging Research program to encourage specialists to consider geriatrics research careers; a new initiative combining medical school with a Ph.D. in behavioral or social science; and the Paul

Beeson Career Development Awards in Aging Research for outstanding clinician-scientists, all exemplify NIA's commitment to excellence and diversity in aging research.

Unfortunately, while the current dollars appropriated to NIA seem to have risen significantly since FY 2003, when adjusted for inflation, they have decreased more than 20 percent in the last ten years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward supporting the work of the NIA- compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases.

We recognize the tremendous fiscal challenges facing our nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the nation's aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

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**Person Submitting Testimony:** Jane Hudson, Executive Director, Disability Rights Iowa,  
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**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human  
Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony  
for the record)

I write today to submit testimony for the record demonstrating the work of Disability  
Rights Iowa, the Protection and Advocacy (P&A) agency for Iowa on community  
integration and ensuring access to services for people with intellectual and  
developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for  
Individuals with Developmental Disabilities (PADD) program have been working to  
ensure that individuals with intellectual and developmental disabilities are free from  
abuse and neglect (both in institutional settings and the community) and that their rights  
and desires are respected and considered as decisions are made concerning  
education, employment, housing, and health care.

In fiscal year 2014, Disability Rights Iowa served 41 individual clients with intellectual or developmental disabilities, held 14 trainings with 641 people trained, and provided informational and referral services to an additional 8 people. In addition to these activities, 7900 people were impacted by the activities undertaken by Disability Rights Iowa on behalf of groups of clients. These activities benefited individuals in every state and territory in the United States.

As an example of the work done by Disability Rights Iowa concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

- **Improving the Juvenile Justice System for Girls.** In 2013, DRI investigated the illegal restraint and seclusion of girls who had been adjudicated delinquent or children in need of assistance and had been placed in the state-owned and operated Iowa Juvenile Home for Girls in Toledo, IA. DRI found that some girls had been placed in concrete prison-like cells for 23 hours per day and were not receiving a free and appropriate public education in violation of the Individuals with Disabilities in Education Act. The Governor established a task force to make recommendations about what the girls needed and how they should be served. After the task force made its recommendations, the Governor closed the home in January 2014 and most of the girls were moved to private comprehensive residential treatment facilities or psychiatric medical institutions for Children. In 2014, DRI continued its systemic advocacy for girls adjudicated delinquent or children in need of assistance. As a result of a state complaint filed by DRI, the

Iowa Department of Education ordered the state Department of Human Services to provide compensatory education for those girls who had not received special education services in accordance with state and federal education laws. DRI also monitored the private facilities to which the girls had been transferred and filed a state education complaint against one of these facilities to bring it into compliance with education laws. In addition, DRI reached out to national experts at the Office of Juvenile Justice and Delinquency Programs in the U.S. Department of Justice to develop a forum to discuss the needs of girls adjudicated delinquent and what changes are needed in Iowa's juvenile justice system to better serve them. This forum, which brought together state and national experts and other stakeholders, occurred on April 6 2015. As a result of these and other efforts, Iowa was one of the three states that received a \$325,000 grant from the National Girls Initiative to improve Iowa's juvenile justice system for girls.

- **Making the Iowa State Fair Accessible**. DRI conducted an accessibility review of the Iowa State Fair and, in 2014, entered into negotiations with the Fair administration to hire an accessibility expert and develop a transition plan to bring the Fair into compliance with the Americans with Disabilities Act. The Fair administration agreed to hire Disability Action Consultants to complete a self-evaluation and transition plan. As a result of an individual service request from the family of a child with a developmental disability, DRI obtained modifications of the Fair's campground reservation policies so that the child could camp with his



family and attend the fair. DRI provided ongoing technical assistance to the Fair Administration regarding the use of service animals on the Fair grounds.

- **Protecting Students with Disabilities against Bullying and Harassment.** DRI sat on the Safe Schools Coalition, which service in an advisory capacity to the safe school certification program. The Coalition focused on building a framework to help guide school districts towards making systemic changes to reduce bullying and harassment of students, including students with intellectual and developmental disabilities. The framework was designed to address two key components of creating safe schools: (1) Policy: ensuring that schools have successful adopted required safe school laws and (2) Practice: providing technical assistance and support around a framework of eight elements that can create policy fidelity and sustain safe school climates: Buy-in; Leadership; Data; Family and Community Engagement; Programs and Practices; Training; Student Engagement and enforcement.
- **Ensuring that Medicaid Recipients Receive Non-Emergency Medical Transportation Services.** DRI has an ongoing systemic project to review the delivery on non-emergency medical transportation (NEMT) services to Medicaid recipients, including children and adults with intellectual and developmental disabilities. In fiscal year 2014, DRI met several times with the member advisory council to discuss ongoing issues and suggest improvements. DRI also reviewed the request for state's request for proposal for new NEMT services and got input from stakeholders regarding denials of NEMT services. DRI also drafted and submitted comments in response to a Request for Information from

the state Medicaid agency addressing member education, grievance policies, customer satisfaction and the state law, which did not extend NEMT to individuals who received Medicaid services in the Medicaid expansion under the Patient Protection and Affordable Care Act. DRI also represented an individual with a developmental disability whose mother transported him to medical appointments. Although his mother completed all reimbursement requests correctly, the NEMT broker alleged that he owed \$3000 for past overpayments and began deducting the amount from future reimbursements. DRI was able to stop this illegal practice.

- **Filing a Complaint regarding the State's Failure to Provide Specialized Services (Active Treatment) to Nursing Facility Residents with Intellectual Disabilities.** DRI filed a complaint with the Centers for Medicare and Medicaid Services (CMS) after DRI found that the State of Iowa, in violation of federal law, was not providing or arranging for the provision of specialized services to nursing facility residents with intellectual disabilities. The complaint is still outstanding. However, the state did agree to contract with screening and evaluation entity to do some follow-up on the provision of specialized services.

Thank you for this opportunity to submit this testimony.



**Testimony Regarding Fiscal Year 2015 Appropriations for  
Title VIII Nursing Workforce Development Programs  
April 28, 2015**

**Submitted by:** Peggy Barksdale, MSN, RN, OCNS-C, CNS-BC, President, National Association of Clinical Nurse Specialists

**To:** Subcommittee on Labor, Health & Human Services, Education, and Related Agencies,  
Committee on Appropriations, U.S. House of Representatives

**Agency Addressed:** Health Resources and Services Administration (HRSA)

The National Association of Clinical Nurse Specialists (NACNS) is the voice of more than 70,000 clinical nurse specialists (CNSs). CNSs are licensed registered nurses who have graduate preparation (master's or doctorate) in nursing as a clinical nurse specialist. They have unique and advanced level competencies that meet the increased needs of improving quality and reducing costs in today's healthcare system. CNSs provide direct patient care, including assessment, diagnosis, and management of patient healthcare issues. They are leaders of change in health organizations, developers of scientific evidence-based programs to prevent avoidable complications, and coaches of those with chronic diseases to prevent hospital readmissions. CNSs are facilitators of multidisciplinary teams in acute and chronic care facilities to improve the quality and safety of care, including preventing hospital acquired infections, reducing length of stays, and preventing hospital readmissions.

The NACNS urges the subcommittee to fund the **Title VIII Nursing Workforce Development Programs at \$244 million in FY 2016.**

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 19.4 percent from 2012 to 2022, outpacing the 11 percent average for most other occupations. BLS also projects that this growth will result in 1,052,600 job openings, representing one of the largest numeric increases for all occupations. With technological advancements driving growth in treatments, preventive care being emphasized more, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year, these are the factors fueling this projected increase in new RN jobs. A particularly alarming element of the probable RN job openings is the anticipated loss of nursing expertise due to the need to replace some 525,700 jobs vacated by RNs who are expected to leave the profession and/or retire from the labor force by 2022.

BLS notes that the healthcare sector is a critically important industrial complex for the nation. It is at the center of the economic recovery with the number of jobs climbing steadily. Growing even when the recession began in December 2007, healthcare jobs are up nationwide. Nearly five million workers are in hospital settings, which often are the largest employer in a state. Health care has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.265 million active, licensed RNs in the United States in 2015.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective health care. NACNS applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

The current federal funding falls short of the healthcare inequities facing our nation today. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a more than 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

NACNS believes that the deepening health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses, advanced practice registered nurses, and qualified nurse educators are addressed. Your support will help ensure that future nurses exist who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing the nation today, an under resourced nurse education and its adverse effect in health care generally will be difficult to avoid.

***In closing, NACNS urges the subcommittee to maintain the Title VIII Nursing Workforce Development Programs by funding them at a level of \$244 million in FY 2016.***

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Testimony on behalf of the  
**Population Association of America/Association of Population Centers**  
 Regarding the Fiscal Year 2016 Appropriation for the  
**National Institutes of Health, National Center for Health Statistics,  
 and Bureau of Labor Statistics**

Submitted to the  
 House Committee on Appropriations  
 Subcommittee on Labor, Health and Human Services and Education  
 By Mary Jo Hoeksema, Director, Government and Public Affairs  
 Population Association of America/Association of Population Centers  
 maryjo@popassoc.org, 202-341-7283

**Introduction**

Thank you, Chairman Cole, Ranking Member DeLauro, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS).

These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In FY 2016, we urge the Subcommittee to adopt the following funding recommendations: at least \$32 billion for the NIH, consistent with the level recommended by the Ad Hoc Group for Medical Research; \$172 million, consistent with the Administration's request; and BLS, \$632 million, consistent with the Administration's request.

The PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and approximately 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, conduct scientific research, analyze changing demographic and socio-economic trends, develop policy recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including adolescent health and development, aging, health disparities, retirement, and labor.

Population scientists compete for discretionary grant funding from the NIH and rely on data from the nation's statistical agencies to conduct research and research training activities.

### **National Institutes of Health**

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

### **National Institute on Aging**

NIA-supported research confirms that by 2030, there will be 72 million Americans aged 65 and older. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well being characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of federal support for basic population aging research.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers on the Demography and Economics of Aging, the NIA BSR Division also supports several large, accessible surveys. For example, the Health and Retirement Study (HRS), provides unique information about economics transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. Since 1992, the HRS has collected data, including, most recently, biomarkers, from a representative sample of more than 27,000 Americans over the age of 50 every two years. These data are accessible to

researchers worldwide and have informed numerous scientific findings. In 2013, researchers using the HRS published a study in the *New England Journal of Medicine*, concluding that the cost of providing dementia care is comparable to, if not greater than, those for heart disease and cancer.

With additional support in FY 2016, the Institute can sustain and expand its investment in population aging research, including launching an initiative to explore why other industrialized countries surpass the United States in health at older ages and longevity. The Institute is also interested in supporting research on the role educational achievement may play in the onset of dementia. Additional funding would also help NIA improve its payline, which, as of January 2015, was only at the 7th percentile for applications under \$500K and at the 4th percentile for applications over \$500K. As members of the Friends of NIA, we urge the Committee to provide the NIH with an additional \$500 million in FY 2016 to support aging research activities not only at the NIA, but also across the agency.

#### **Eunice Kennedy Shriver National Institute on Child Health and Human Development**

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and research training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents, and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. In 2014, scientists, using data from these large-scale data sets published numerous findings. For example, researchers using both genetic and survey

data from the Fragile Families study found that poverty and unstable family environments shorten chromosome-protecting telomeres in young African American boys as compared to children from nurturing environments. This finding provides new insights into the insidious role chronic stress plays in child health.

NICHD supports the Population Dynamics Centers Research Infrastructure Program, which promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists. The Association of Population Centers produces an annual guide describing the centers' activities and accomplishments. As members of the Friends of NICHD, PAA and APC request that the Institute receive a funding level of at least \$1.37 billion in FY 2016. With additional support, NICHD can build upon successful research while prioritizing and investing in new research such as the Human Placenta Project.

### **National Center for Health Statistics**

The National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the states to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey and National Survey of Family Growth. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.



The Subcommittee's support of NCHS in recent years has enabled it to make significant progress toward modernizing the NVSS, moving many states from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. As members of the Friends of NCHS, PAA and APC request that NCHS receive \$160 million in budget authority in FY 2016. We also endorse the Administration's proposed increase of \$12 million in Prevention Fund funding for NCHS in FY 2016. This funding would allow NCHS to continue expansions to questions and sample sizes in the National Health Interview Survey and expansions in sample sizes in the National Ambulatory Medical Care Survey (NAMCS). Without the Prevention Fund allocation in FY 2016, these survey enhancements will discontinue, jeopardizing the utility of these important datasets.

### **Bureau of Labor Statistics**

BLS produces essential economic information for public and private decision making. Its data are used extensively by population scientists who study and evaluate labor and related economic policies and programs. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets the population sciences use to understand how complex factors, such as changes in work status, income, and education, interact to affect health and achievement outcomes in children and adults.

Since FY 2010, the BLS budget has decreased by 10 percent, taking into account inflation. Its bleak fiscal outlook has forced the agency to cut or curtail surveys and put some its programs, such as the export pricing program, in serious jeopardy of complete elimination. Given the importance and unique nature of BLS data, we urge the Subcommittee to support the Administration's request, \$632 million, an increase of \$41 million above the FY 2015 funding level.

Submission by Susan Kreutzer, patient advocate and advisor for [MEAdvocacy.org](http://MEAdvocacy.org)<sup>1</sup>

**The National Institute of Health's funding and handling of myalgic encephalomyelitis (ME) urgently needs overhauling. We are asking for \$250 million a year to bring ME funding up to an appropriate level.**

Myalgic encephalomyelitis (ME), also known in the U.S. as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a seriously disabling neuro-immune disease. It sickens an estimated 850,000 to 2.5 million<sup>2</sup> in the U.S. and 17 million worldwide. A majority of patients are disabled, unable to work, attend school or participate in activities of daily life. A quarter are so severely affected as to render them bedbound, unable to care for themselves.

The disease has a long history, appearing worldwide in epidemic and endemic forms. Myalgic encephalomyelitis was described, defined and coined by Dr. A. Melvin Ramsay after a 1955 outbreak in London. The first major clusters reached the U.S. in the mid-1980s in Incline Village, Nevada and Lyndonville, New York. In response, the CDC broadly redefined the disease and renamed it the marginalizing name; chronic fatigue syndrome (CFS).

For the past three decades, ME patients' voices have been ignored. The Department of Health and Human Services (HHS) has continuously attempted to bury this disease, by neglecting and marginalizing the patients. To accomplish this, HHS has repeatedly

used overly broad definitions, trivializing disease names, and grossly underfunded it. This has resulted in substandard care for ME patients by the medical community, leaving a generation of ME patients suffering with little hope for the future. Unconscionably, the upcoming generation of patients are facing the same issues as thirty years ago.

[MEAdvocacy.org](http://MEAdvocacy.org)<sup>1</sup> is a growing grassroots movement of advocates and patients who are rising up and saying we have had enough of empty promises and lies. We want the right to life, liberty, and the pursuit of happiness that is afforded to us by the Declaration of Independence. We want the same chance at life and health as patients who suffer from other similarly burdened diseases. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this debilitating disease and we have no hope of treatment or cure. We have had enough and are saying, **“No More!”**

### **Disease Burden and Funding:**

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, dismissed and stigmatized by the medical community. The patients will not carry this burden quietly any longer and we are looking at Congress to require HHS to properly fulfill their duty to ME sufferers. If you do not act on behalf of these severely affected patients, you are complicit in their suffering and untimely deaths.

In 2006, Dr. Nancy Klimas, then the director of AIDS research at the Miami Veterans Affairs Medical Center as well as a CFS researcher/clinician stated in a press conference, "They [ME/CFS patients] experience a **level of disability equal to that of patients with late-stage AIDS and patients undergoing chemotherapy.**" In the intervening years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the Appropriation Committee, for help in addressing this dire need for funding, oversight and investigation.

It is estimated that the burden to the economy for ME is between \$17 to 24 billion,<sup>3</sup> yet NIH funding for research has stagnated at a mere \$5 million a year. HHS has placed funding for ME at the rock bottom of their funding budget list.<sup>4</sup> The yearly allocation for ME/CFS is a tiny fraction of what other similarly burdened diseases receive.

<i>NIH Funding Data for 2014</i>	<i>US Patient Population</i>	<i>Funding per Patient</i>
<i>HIV/AIDS - \$ 2 billion, 978 million</i>	<i>1,200,000</i>	<i>\$2,481</i>
<i>multiple sclerosis - \$ 102 million</i>	<i>400,000</i>	<i>\$255</i>
<i>lupus - \$ 99 million</i>	<i>350,000</i>	<i>\$283</i>
<b><i>myalgic encephalomyelitis - \$5 million</i></b>	<b><i>1,000,000</i></b>	<b><i>\$5</i></b>

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the 77 recommendations made by the Chronic Fatigue Syndrome Advisory Committee (CFSAC)<sup>5</sup> during the past ten years. The department did not heed the call by President Obama<sup>6</sup> as a result of a call out at a town hall meeting by the wife of a patient. In order to fund ME on par with MS, a similarly serious disease, ME would need \$250 million a year. Perhaps a proportional allocation from other diseases related to immune, cognitive and nervous system dysfunctions could be utilized by this committee to find the additional funding needed for ME.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that NIH meet, in order to bring myalgic encephalomyelitis on par with other similarly burdened diseases:

1. **Fund biomedical research for ME commensurate with its severity and burden** to patients and the economy. We are asking for specific funding in the amount of **\$250 million**, the amount we believe is needed to bring ME funding to an appropriate level. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished **by means of prorating the allocation** from other diseases related to immune, cognitive and nervous system dysfunctions.

2. Return ME to the National Institute of Allergy and Infectious Disease (NIAID) or place it in the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as multiple sclerosis.

The **Office of Research on Women's Health, where ME is currently housed, is entirely inappropriate** for a disease which also strikes men and children.

Very truly yours,

Susan A. Kreutzer

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Links
1) <a href="http://www.meadvocacy.org/">http://www.meadvocacy.org/</a>
2) <a href="https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf">https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf</a>
3) <a href="https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf">https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf</a>
4) <a href="http://report.nih.gov/categorical_spending.aspx">http://report.nih.gov/categorical_spending.aspx</a>
5) <a href="http://www.hhs.gov/advcomcfs">http://www.hhs.gov/advcomcfs</a>
6) <a href="https://dl.dropboxusercontent.com/u/89158245/President-Obama-Letter-on-CFS.pdf">https://dl.dropboxusercontent.com/u/89158245/President-Obama-Letter-on-CFS.pdf</a>

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## Association of American Cancer Institutes

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**Statement by the Association of American Cancer Institutes on  
Fiscal Year (FY) 2016 Appropriations for the Department of Health and Human Services  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Committee on Appropriations, U.S. House of Representatives**

*Testimony submitted by:*

**Barbara Duffy Stewart, MPH, Executive Director**

**(412) 647-2076, [barbara@aacr-cancer.org](mailto:barbara@aacr-cancer.org)**

The Association of American Cancer Institutes (AACI), representing 94 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the subcommittee. AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) in the amount of at least \$32 billion for FY 2016, including a proportional increase of \$5.32 billion for the National Cancer Institute (NCI).

AACI thanks Congress for its enduring commitment to guaranteeing quality care for cancer patients, as well as for providing researchers with the resources that they need to develop better cancer treatments and, ultimately, to find cures. The partnership between the federal government and our nation's cancer centers is mutually beneficial, and cancer centers continue to make strides in biomedical research thanks to the support of the federal government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

The President's FY 2016 budget request for the NIH is \$31.3 billion, \$1 billion (3.3 percent) above the enacted FY 2015 level. This includes \$5.098 billion for the NCI. In his budget blueprint, the President also outlined the Precision Medicine Initiative, which includes an investment of \$215 million: \$130 million would be provided to the NIH to support a national research component; \$70 million to the NCI to support additional cancer genomics research

efforts; \$10 million provided for the Food and Drug Administration (FDA) to support regulatory efforts related to precision medicine; and \$5 million to the Office of the National Coordinator for Health Information Technology for data privacy and interoperability efforts.

While the President's proposed budget would allow for more competing Research Project Grants (RPGs), direct budget cuts in 2011 and 2013 continue to impact labs nationwide. If Congress fails to act, sequestration will impair biomedical research in FY 2016 and for years to come. Ongoing budget constraints continue to drive promising young scientists to research opportunities abroad or outside of the biomedical research community. Veteran researchers have been forced into early retirement, and many labs coping with decreased funding have had to prioritize research projects. The threat to America's standing in research and development is threatened with each dollar slashed from the NIH budget.

With each cut, cancer centers are challenged to provide infrastructure resources necessary to support their labs, and the failure to keep pace with the biomedical inflation rate will limit AACI members' ability to provide well-functioning shared resources to investigators who depend on them to complete their research. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared resources that are essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants. Center infrastructure is expensive and it is not clear where cancer centers would acquire alternative funding if NCI grants for these efforts continue to dwindle.

### **Research Support Has Diminished but Cancer Continues to Plague America**

Since 2003, the NIH budget has dropped 24 percent (\$6.5 billion), when accounting for inflation in the cost of biomedical research. The outlook has been just as damaging for the NCI,



with its budget cut 26.4 percent (\$1.2 billion) since 2003. The President's FY 2016 proposal falls far short of the inflation rate of 2.4 percent, a figure that NIH projected for the FY 2016 Biomedical Research and Development Price Index (BRDPI).

AACI cancer centers are at the forefront of the national effort to eradicate cancer. The cancer centers that AACI represents house more than 20,000 scientific, clinical and public health investigators who work collaboratively to translate promising research findings into new approaches to prevent and treat cancer. Making progress against cancer is complex and time-intensive. However, the pace of discovery and translation of novel basic research to new therapies could be quickened if researchers could count on an appropriate and predictable investment in federal cancer funding.

Flat funding to the NIH continues to impede advances in biomedical research and also undermines cancer centers' ability to: conduct and support multidisciplinary cancer research; train cancer physicians and scientists; provide state-of-the-art care; and, disseminate information about cancer detection, diagnosis, treatment, prevention, control, palliative care, and survivorship across our communities.

With excitement mounting about the scientific opportunities ahead and our potential to leverage the resulting advances to help our fellow citizens, now is not the time to retreat from fully funding the NIH and NCI. The broad portfolio of research supported by NIH and NCI is essential for improving our basic understanding of diseases and has considerably improved Americans' health. A sound investment by the federal government in biomedical and cancer research over the past two decades has led to incredible advances in our understanding of cancer, and to new ideas that have the potential to accelerate that progress faster than ever before.

Cancer is one of the leading causes of death and disability in the United States. This

year, more than 1.6 million Americans will receive a cancer diagnosis and more than 589,000 Americans will lose their lives to cancer. Despite these alarming numbers, they represent progress. The five-year relative survival rate for all cancers diagnosed between 2002 and 2008 is 68 percent, up from 49 percent between 1975 and 1977. In addition, cancer death rates have dropped 11.4 percent among women and 19.2 percent among men over the past 15 years.<sup>1</sup> The improvement in survival reflects both improvement in diagnosing certain cancers at an earlier stage and better treatment.

Our country has contributed to a steady decrease in the mortality rate for cancer. More Americans than ever are living through and beyond a cancer diagnosis and the potential for accelerating progress against cancer is greater than ever.<sup>2</sup> However, cancer incidence worldwide is expected to increase from 12.8 million new cases in 2008 to 22.2 million in 2030. The NCI estimates that 41 percent of individuals born today will receive a cancer diagnosis at some point in their lifetime.<sup>3</sup> The time for predictable federal funding for the NIH is now.

### **Conclusion**

The NIH estimates that the overall costs of cancer in 2013 were \$263.8 billion: \$124.6 billion for direct medical costs (the total of all health expenditures) and \$139.2 billion for indirect mortality costs (due to lost productivity due to premature death).<sup>4</sup> Even as the cost of cancer continues to rise, investment in cancer research could one day significantly reduce or even eliminate the health and economic burdens that cancer imposes on all Americans. Failure to keep pace with the biomedical rate of inflation will only hinder our nation's cancer center

<sup>1</sup> American Cancer Society. Facts and Figures, 2015. <http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2015/>

<sup>2</sup> American Cancer Society. Facts and Figures.

<sup>3</sup> *Cancer Trends Progress Report – 2011-2012 Update*, National Cancer Institute, NIH, DHHS, Bethesda, MD, August 2012, <http://progressreport.cancer.gov>.

<sup>4</sup> American Cancer Society. Facts and Figures.

researchers from generating future knowledge that will aid in the prevention, detection and treatment of cancer.

AACI joins with our colleagues in the biomedical research community in recommending that the subcommittee recognize the NIH as a critical national priority by providing at least \$32 billion in funding in the FY 2016 Labor-HHS-Education Appropriations bill, including an equivalent percentage increase in funding for NCI. This funding level represents the minimum investment necessary to avoid further loss of promising research.

A sound federal investment in our nation's NCI-designated cancer centers and emerging academic cancer centers will continue to accelerate progress and promote future advances that will ensure a healthier, more productive future for the benefit of all cancer patients. This is an important moment in America's commitment to finally defeat the more than 200 diseases we call cancer –and to ultimately transform cancer care for the millions of men and women touched by cancer.

April 28, 2015

To: U.S. House of Representatives Committee on Appropriations  
 Subcommittee on Labor, Health & Human Services, Education and Related Agencies

I am writing as a person with a disability on behalf of the Atlanta Chapter of the Autistic Self Advocacy Network to support continued appropriations to support Home and Community-Based Services (HCBS) and community integration-related activities, including efforts that would lead to downsizing or closure of institutional or segregated facilities such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), congregate residential facilities, sheltered workshops, or segregated day habilitation programs. These activities may be conducted by any component of HHS, including the Administration on Intellectual and Developmental Disabilities (AIDD), the National Council on Disability (NCD), and the Centers for Medicare & Medicaid Services (CMS). Far from depriving individuals of choice, these efforts help to rebalance public spending toward the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Community integration efforts help bring federal funding for disability-related services into alignment with the 1999 *Olmstead* decision, which requires services to be delivered in the most integrated setting possible. Many people with disabilities who need long-term services and supports continue to be forced into nursing facilities and other institutions against their will because adequate community-based services were not available. Segregated and institutional settings are rife with opportunities for abuse, in addition to being significantly more costly than community-based settings.

An essential component of community integration efforts is enforcement of regulations that ensure that federal funds specifically earmarked for integration are not used to fund institutional or segregated placements. In order to make community-based services available, it is often necessary to rebalance funding toward community-based services as opposed to institutional settings. For example, Congress authorized federal reimbursement to states who provide Home and Community-Based Services through their Medicaid programs. HCBS programs were designed specifically to promote fully integrated service delivery settings in the community—in other words, supporting the self-determination of people with disabilities by providing meaningful choices for where they can live, work, and receive services in their own homes and communities. It is vitally important that HCBS funds are not used for any settings, programs, or types of services that are not truly integrated and based in the community. Inclusion of any language prohibiting use of congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice and force them to live and receive services in restricted and segregated settings instead of the community.

People with disabilities have fought for decades to make meaningful choices about community-based options a reality. We believe that all people should have the right to stay in their own communities, and that it is imperative for the past several decades' move away from institutions to continue. I urge the Appropriations Committee to ensure that HHS is able to continue its vital work on HCBS implementation and community integration. This work will ensure that many

more people with disabilities have the opportunity to transition out of unnecessarily restrictive settings and live in fully integrated communities.

Sincerely,

Kathleen “Kit” Mead  
Chapter Leader, The Autistic Self Advocacy Network of Atlanta

Atlanta, GA

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**Testimony of Wendy Spencer  
Chief Executive Officer  
Corporation for National and Community Service**

*Before the*

**Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies,  
Committee on Appropriations  
United States House of Representatives**

**Hearing on the President's Fiscal Year 2016 Budget Request  
April 22, 2015**

Chairman Cole, Ranking Member DeLauro, and Distinguished Members of the Subcommittee,

Thank you for the invitation to testify today. It is an honor to appear before you to present the Administration's fiscal year 2016 budget request for the Corporation for National and Community Service (CNCS). I appreciate the opportunity to tell you about our work to improve lives, strengthen communities, expand economic opportunity, and engage millions of Americans in service to meet pressing national challenges.

We are grateful for the funding Congress provided in fiscal year 2015 to support our mission. And I am personally grateful to the Chairman and other members of the Subcommittee for meeting with me to discuss the work our national service and social innovation programs are doing in your districts and ways to expand those efforts.

I appear before you today with a great sense of pride and optimism about the contributions of our national service members and volunteers, their impact on national challenges, and our agency's vital role in strengthening citizen service and community solutions across the country.

In 2014, we engaged approximately 270,000 Senior Corps participants, 75,000 AmeriCorps members, and millions of community volunteers in solving local problems. Our Social Innovation Fund leverages substantial non-federal support for the growth of evidence-based programs that improve the lives and build the economic independence of low-income individuals.

As CEO, I am privileged to work every day with a talented team at CNCS and alongside extraordinary, mission-driven leaders in our field as well as the passionate, committed individuals who serve in our programs. Here are a few I have met.

- Elizabeth Oliver joined AmeriCorps VISTA after learning about the plight of homeless veterans as a college student. At age 20, she moved to Salt Lake City to begin a year of service with The Road Home, Utah's largest homeless shelter. Elizabeth worked with Mayor Becker's office to identify and recruit new landlords who were willing to house veterans. As a result of her efforts, 97 homeless veterans gained housing. Her work was central to Salt Lake City becoming one of the first cities to end chronic veteran's homelessness – an achievement that has inspired 355 other mayors to commit to ending veteran homelessness this year.
- On May 20, 2013, within hours after a devastating tornado struck Moore, Oklahoma, AmeriCorps and Senior Corps arrived on the scene. FEMA Corps, a branch of AmeriCorps NCCC, immediately deployed nearly 50 members to conduct damage assessments. Senior Corps RSVP volunteers answered disaster hotlines, served food at shelters, and assisted survivors. When I was there shortly after the tornadoes, I saw in action the 187 AmeriCorps and Senior Corps participants who, over the next two months, collected and distributed 475,000 pounds of donations, conducted 651

damage assessments, and mobilized 3,000 volunteers. Last month, after another tornado struck Moore, our members were back in action, supporting call centers, conducting intakes, and coordinating volunteers.

- Chrysalis, a Los Angeles nonprofit supported by our Social Innovation Fund grantee REDF, is dedicated to creating a pathway to self-sufficiency for homeless and low-income individuals. It operates an evidence-based, social enterprise program that provides transitional jobs to adults facing employment barriers. Chrysalis helps people like Eric gain skills to re-enter the job market. Eric spent 15 years living on Skid Row, going in and out of jail, struggling with substance abuse. In 2013, he knew he had to change. He tried for months to find a job, but with his background, no one would hire him. Then he came to Chrysalis and found transitional employment. Now Eric is off the streets, off drugs, and employed full-time. A recent evaluation found that one year after accepting a social enterprise job through organizations such as Chrysalis, workers like Eric had their average income monthly income grow by 91 percent while their income from government benefits dropped from 71 percent to 24 percent.
- Forty-four AmeriCorps members serve with Operation UNITE, a nonprofit started by Congressman Hal Rogers in 2003 to address the scourge of prescription drug abuse in his rural Kentucky district. AmeriCorps members provide math tutoring, teach drug prevention, and lead anti-drug clubs in 42 schools. Last year AmeriCorps members tutored 2,150 students, mentored 3,200 students, and mobilized 2,100 volunteers. Operation UNITE's performance measures showed that the math test scores for the students tutored by AmeriCorps members increased by 34 percent and when I traveled with the Chairman to an elementary school in Staffordsville, we heard over and over from principals and teachers how indispensable AmeriCorps members were to helping at-risk students increase test scores, improve behavior, and get on track to graduate.

### **CNCS'S CORE PRINCIPLES**

These stories happen every day and are made possible by the funding that Congress provides. These examples illustrate our focus on a set of smart, common sense principles:

- **Empowering Citizens to Solve Problems:** Our agency was created on a fundamental idea – that our nation is stronger when we harness the ingenuity and can-do spirit of our people. AmeriCorps members and Senior Corps volunteers are dedicated citizens who work hard in tough conditions. They make an intensive, sustained service commitment. Because of this, they can serve as the backbone for engaging community volunteers and helping nonprofits and local governments tackle their most pressing challenges. AmeriCorps and Senior Corps participants take on complex assignments, recruit and manage volunteers, assume leadership roles, and deliver powerful results.
- **Expanding economic opportunity:** By helping seniors live independently, or keeping students on track to graduate, or connecting returning veterans to jobs, CNCS's programs increase economic



independence and build family stability. National service is also a pathway to education and employment for those who serve. Since 1994, AmeriCorps members have earned \$2.87 billion in education awards to reduce student loan debt or pay for college, further education or training. AmeriCorps members gain valuable skills including leadership, project management, and problem-solving that all employers look for. As part of their service, many AmeriCorps members also receive valuable certifications such as First Aid, CPR, teaching, disaster response, and firefighting. Employers recognize the valuable skills that participants build through national service: since it launched last fall, 200 employers, who together have more than one million employees, have become Employers of National Service. Employers that participate in this initiative commit to specifically recruit AmeriCorps alumni to develop a talent pipeline into their workforce. These employers, including Disney, Comcast and NBC Universal, CSX, and the States of Montana and Virginia, know that AmeriCorps alumni are dedicated, talented, and mission-driven, and they want more on their teams.

- **Supporting Local Control and Community Solutions:** National service recognizes that many of the best solutions come from outside Washington. Funding and decision-making is often pushed to the state and local level. Governors play a key role in deciding where national service resources go, with two-thirds of AmeriCorps funds currently overseen by Governor-appointed State Service Commissions. Local organizations selected for CNCS funding are responsible for recruiting, selecting, and supervising their participants. These participants serve at more than 60,000 locations – schools, food banks, homeless shelters, youth centers, and veteran’s facilities – helping organizations expand their impact through direct service, by mobilizing volunteers, and by strengthening the capacity of the organizations where they serve. National service bolsters — not displaces — the civic, neighborhood, and faith-based organizations that are essential to our communities.
- **Leveraging Resources Through Public-Private Partnerships:** Each year, CNCS programs generate more than \$800 million in outside resources from businesses, foundations, and other sources. Businesses that provide matching support include leading companies like Google, Walmart, Target, Comcast, Bank of America, Cisco, Microsoft, and Home Depot – along with thousands of small businesses, community foundations, and local agencies that see national service as a smart, cost-effective investment. This local investment strengthens community impact and increases the return on taxpayer dollars.

## **2016 BUDGET PRIORITIES**

The President’s 2016 Budget builds on these core principles and our decades of experience in engaging citizens in national service, social innovation, and volunteerism. The request of \$1.18 billion will support CNCS and its thousands of state and local partners in meeting community needs with higher levels of impact, evidence, accountability, and efficiency. These investments are possible because the

President's Budget reverses sequestration, which means that there are resources available for national service and other important initiatives.

Within our budget, we have three key priorities: expanding service opportunities and community impact; funding what works using evidence and competition; and ensuring accountability and efficiency.

### **EXPANDING SERVICE OPPORTUNITIES AND COMMUNITY IMPACT**

The first priority is to expand service opportunities and increase our impact on local and national challenges. The budget supports approximately 90,150 AmeriCorps members to address the priorities that Congress identified in the Serve America Act: disaster services, economic opportunity, education, environmental stewardship, healthy futures, and veterans and military families. Within this increase, the budget proposes three new initiatives that build on past success to meet emerging needs:

- **Opportunity Youth:** The budget would provide opportunities for 13,000 youth from underserved backgrounds to serve as AmeriCorps members during the summer. This will give more underserved youth the opportunity to meet community needs as they develop job skills, explore potential career paths, and earn a stipend and education award they can use for college. To maximize outcomes, the budget proposes legislative language to lower the AmeriCorps age limit to 14 for this initiative.
- **Encore Initiative:** The budget proposes 4,000 Encore positions to encourage more retired Americans to apply their lifetime of skills and experiences to solve community problems through AmeriCorps service. This will move toward the Serve America Act goal of having people over age 55 account for 10 percent of AmeriCorps members.
- **Resilience Corps:** Building on the success of the President's Task Force on Expanding National Service, the budget funds a new partnership with the National Oceanic and Atmospheric Administration to enlist roughly 200 AmeriCorps members to support local leaders as they plan for and address the impacts of extreme weather and climate effects in their communities.

The Budget also supports opportunities for 270,000 older Americans to serve in Senior Corps programs as Foster Grandparents, Senior Companions, and RSVP volunteers.

CNCS will continue to seek partnerships with corporate and philanthropic communities and federal agencies to expand AmeriCorps and Senior Corps service opportunities. Recent partnerships have committed up to \$35 million in additional resources to address national and local priorities, creating approximately 4,500 new AmeriCorps service positions. This approach stretches limited federal dollars.

## **FUNDING WHAT WORKS USING EVIDENCE AND COMPETITION**

Our second priority is maximizing the return on federal investments by increasing competition and using evidence in budget, management, and grantmaking decisions.

**Using Evidence to Drive Impact:** CNCS currently operates two competitive grant programs that explicitly incorporate demonstrated evidence of effectiveness into funding decisions. These programs – AmeriCorps State and National and the Social Innovation Fund (SIF) – account for the largest share of CNCS program funding. The 2016 budget will continue the focus of these programs on competitive grantmaking that prioritizes evidence-based models. All SIF programs must be able to demonstrate a preliminary level of effectiveness before they are funded and then take part in a rigorous evaluation to strengthen their evidence base. The budget continues to allow the use of up to 20 percent of SIF funds to support Pay for Success projects. Pay for Success models leverage philanthropic and private dollars to fund services up front, with government paying only after results occur.

Through this budget, we build the capacity of grantees to use evidence and evaluation to strengthen outcomes, support the dissemination of effective practices to the broader nonprofit sector, and strengthen performance reporting by our grantees. We will continue to support research and evaluation on agency programs such as the recent evaluation of the Minnesota Reading Corps, AmeriCorps’ largest tutoring program. This rigorous two-part evaluation, conducted by NORC at the University of Chicago, provided compelling evidence that students tutored by AmeriCorps members achieved significantly higher literacy levels than students without such tutors. For example, the average kindergarten student with an AmeriCorps tutor performed twice as well as students without one. The study also concluded that the impacts were statistically significant even among students at higher risk for academic failure and that the Reading Corps model was highly replicable.

**Increasing Competition in Senior Corps:** The budget advances the adoption of evidence-based models by introducing competition into the Foster Grandparent and Senior Companion Programs and enhancing competition in RSVP. Competition increases the impact of federal appropriations by awarding grants to the highest quality grantees. In turn, competition encourages innovation, increases efficiency, and produces greater outcomes for both service participants and service recipients. If enacted, CNCS will provide technical assistance to current grantees to prepare for this change, as we did during the successful introduction of competition into RSVP. The Budget also provides opportunities for Senior Corps grantees who adopt evidence-based models to grow through AmeriCorps.

## **ENSURING ACCOUNTABILITY AND INCREASING EFFICIENCY**

Finally, and most importantly, an overarching priority across all of our work is ensuring accountability and increasing efficiency in our program and financial operations. The strong stewardship of federal

funds is a top priority for me in everything that we do. I am committed to using taxpayer dollars transparently and efficiently in achieving CNCS's mission. To do this, we have built a culture of accountability among our staff and grantees and put systems in place to manage risk, fortify internal controls, and strengthen oversight and monitoring. To that end, we created an Office of Accountability and Oversight which established an Integrity Framework to prevent waste, fraud, and abuse of funds. This framework reflects an enterprise-wide approach to ensuring checks and balances that will enable us to remain effective, efficient, and accountable managers of the taxpayer dollars entrusted to us.

We are also committed to increasing efficiency and stretching our dollars to better support our programs in the field. Among other steps, we are enhancing IT systems, streamlining operations, making grants processes more nimble and user-friendly, and developing tools to work faster and smarter.

## **CONCLUSION**

Mr. Chairman, for more than two decades, the Corporation for National and Community Service has tapped our nation's greatest resource—the American people—to get things done.

Our programs empower citizens to solve problems. They bolster the institutions of civil society. And they expand opportunity through hard work and personal responsibility.

The 2016 budget will continue this smart approach by engaging millions of Americans in meeting critical community needs with higher levels of impact, evidence, and accountability.

Thank you again for inviting me today. I am happy to respond to your questions.

**Written Testimony for the Record of Edward A. Carraway  
Legislative Liaison  
DSI Supporters, Inc.  
P.O. Box 15334  
Submitted to the Senate Appropriations Subcommittee on Labor, Health & Human  
Services, Education and Related Agencies**

Subcommittee lawmakers have the chance to do right by some of our Country's most vulnerable citizens by prohibiting federally funded HHS agencies from using those federal dollars to close Medicaid facilities ("ICFs") serving people with intellectual disabilities. We acknowledge that it is not an easy choice, but it is the right choice.

We argue that forced "deinstitutionalization" activities are contrary to federal law and cause human harm, resulting in many documented cases, as provided below, with doubled, tripled and quadrupled mortality rates. And for those who remain as a facility is being closed often the services are not as best practices demand.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of federal funding.

Often citing the U.S. Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

Justice Kennedy noted in his concurring opinion, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191. "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's Amici Curiae brief]." *Id.*

As Justice Kennedy's concurring opinion is quite clear, as to Choice of Residential Services and the best support systems which addresses each individual's quality of life issues and continuity of care and in compliance with the ADA, Federal Medicaid Act and Developmental Disabilities Assistance and Bill of Rights Act.

For years many states have not allowed new residents family or guardian to choose Public ICF's as they do not advertise this choice as a right to choose, and the availability thereof, as all public ICF's have vacancies. For instance the State of Florida has been guilty of this for years, and without public hearings or notice to families or guardian immediately, starts transitioning to community facilities without transition compatibility trials, and often with

substandard care and qualified professionals available as to needs and timing of its availability. Often Emergency rooms become a replacement for services by public ICFs.

Here are some examples of the recent past.

An audit provided by my home state Florida, who returned over \$80,000,000 to the Treasury last year, where the statistics spread sheet provided has 20,940 individuals with syndromes, conditions, and challengers on the wait list and more than 1300 of those with intensive needs on a wait list who would qualify for public ICFs if family were made aware of such. A few years ago they returned almost \$100,000,000 designated. And many families would like to place their family member in a public ICF as it decreases the chances of them becoming “couch potatoes” as such have recreational facilities, Special Olympics, worship facilities, swimming and therapeutic pools, daily therapists, counselors, prescriptions available, medical staff on duty 24/7, most of all Dentistry, hobby shops, training job skills, with support and participation of many organizations in the community. And facilities designed for the residents to safely walk and roam with security provided 24/7. And equipped to work with all phases of life from pediatric to hospice stage with licensed and trained staff as required by those with DD/ID/MH dual diagnosed. These are very limited in group homes as individuals must be transported to doctors and/or emergency rooms at great cost to their care. For some, emergency rooms can become their care provider due to timing and urgency and limited number of doctors who accept Medicaid and geographical desirability.

### **Mortality media report on deaths after Deinstitutionalization.**

ARC Attorney in Pennsylvania posits a few tragedies are the price of progress”.... so  
*what if a few people died being transferred from larger settings to smaller ones...*

INDIANA: Parents told to drop disabled kids at shelters; State budget cuts have left families with no affordable care options

Summary: The Arc of Indiana's website boasts that Indiana is the. “largest state without state institutions for people with developmental disabilities”. The article below reports that the waiting list of home and community based waiver services exceeds 10,000 people, with some families waiting for 10 years for service, and additional service cuts predicted as a result of budget deficits. As a result, some families desperate for services have been referred to homeless shelters. 10,000 + people on a waiting list, no public ICFs/MR, and homeless shelters. The connection seems clear.

KENTUCKY: Organization sues for access to records of individual who died following community setting Kentucky's Council on Developmental Disabilities (NOT the state's DD Council) filed a lawsuit against the Cabinet for Health and Family Services August 19 for denying access to records for an individual with developmental disabilities who died after being transitioned to a community placement. What do they have to hide?

NEBRASKA: 10 deaths--nine months.



Nebraska Radio Report November 2009. In nine months a 10th person has died from among 47 "medically fragile" residents, an alarming rate of almost one out of five who were moved from Beatrice State Development Center last February. Residents and Families were given very little notice. Residents who were transferred have filed a lawsuit.

VIRGINIA: Community placement doubles mortality rate

*News and Advance (Lynchburg, VA) \* March 11, 2015*

In her March 1 letter to the editor, Commissioner Debra Ferguson, of the Department of Behavioral Health and Developmental Services, stated, "Safety and care of those with intellectual disabilities are our paramount concerns", yet the schedule for training center closures and the actions of the department she leads indicate otherwise.

Data provided by the department last fall to the Virginia Senate work group and posted on its website were sufficient for me to perform an analysis comparing the mortality rate of those who have left training centers with a similar population of those who remained. My analysis showed that the mortality rate of those who left was double that of those who stayed. Meanwhile, discharges progress without hesitation.

Again; Subcommittee lawmakers have the chance to do right by some of our Country's most vulnerable citizens by prohibiting federally funded IHHS agencies from using those federal dollars to close Medicaid facilities ("ICFs") serving people with intellectual disabilities. We acknowledge that it is not an easy choice, but it is the right choice.



To: Members of the U.S. House of Representatives Labor, Health and Human  
Services, Education, and Related Agencies Appropriations Subcommittee

From: Thomas Diedrick, Executive Director

Date: April 28, 2015

*Options* for Independent Living, Inc., a non-profit, non-residential organization assists people with disabilities and those who are older to live in their community. As part of the National Council on Independent Living (NCIL), we are requesting an additional \$200 Million Dollars in funding for independent Living Centers (ILC's). ILC's play in critical role in the lives of people with disabilities and those who are older as well as their respective communities.

From 2012-2014, ILC's provided the four core services to nearly 5 million individuals with disabilities. In that same period, ILC's moved 13,030 people out of nursing homes and institutions, and provided services such as housing assistance, transportation, personal care attendants, and employment services, to hundreds of thousands of people with disabilities. Every day, ILC's are fighting to ensure that people with disabilities gain and maintain control over our own lives.

We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. It's time to get rid of outdated, paternalistic attitudes and allow people with disabilities REAL choice in where and how they live, work, and otherwise

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[www.optionsil.com](http://www.optionsil.com)



participate in the community. The 13,030 people ILC's successfully transitioned out of nursing homes and institutions from 2012-2014 clearly prove that deinstitutionalization works.

Congress demonstrated their understanding and support for this when WIOA was passed and transition was added as a fifth core service. However, with IL being the only federally funded program mandated to provide transition services, the need for funding is critical! Moreover, ILC's need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. Right now, the Independent Living Program is receiving nearly \$3 million less in funding than we were in 2010. Yet, the ILC's are asked to do more by providing the fifth core service as well as maintaining and increasing the services currently being provided. This is simply unacceptable.

*Options* has been providing independent living services to a 17 county area of Northeast Wisconsin and the Fox Valley since 1980. As funding at the State levels increased to allow people with disabilities and those who are older to have home support services versus instructional placement, so have requests for our services. The types of services requested and needed evolved and changed, thus *Options* made those changes in services to meet the needs of the community. We have developed relationships and collaborative partnerships with area non-profit agencies, thus avoiding duplication of services.

With additional funding, we can make a greater impact in the area of "transition." By assisting those in institutions to move into the community, the cost savings to the State and Federal Agencies will decrease dramatically.

You have at this time an important opportunity before you. Increase the funding by \$200 Million and:

- 1) Meet the needs of people with disabilities and those who are older by allowing them the opportunity to live in their community
- 2) Save the States and Federal Government funding for long-term care costs.

Community living is far less costly than institutions.

Thank you for taking these comments into consideration.

Cc: Senator Tammy Baldwin

Senator Ron Johnson

Representative Reid Ribble

**STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM**  
**SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS**  
**SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES**  
 April 29, 2015

This statement includes the Fiscal Year 2016 (FY 2016) requests of the nation's Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

**Department of Education**

**I. Higher Education Act Programs:**

- **Strengthening Developing Institutions:** Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. The TCUs, which by any definition are truly developing institutions, are funded under Title III-A Sec. 316 and provide quality higher education opportunities to some of the most rural/isolated, impoverished, and historically underserved areas of the country. The goal of HEA-Titles III/V programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III-A program is specifically designed to address the critical, unmet needs of American Indian/Alaska Native (AI/AN) students and their communities, in order to effectively prepare them to succeed in a globally competitive workforce. ***We request that the discretionary funding for HEA Title III, Sec. 316 be restored to \$30,000,000 in FY 2016.***

Additionally, we ask that language be included clarifying that funds awarded under Title III, Sec. 316 shall remain available for an additional five years beyond the initial grant period, which is the case for grants awarded under the Historically Black Colleges and Universities (HBCUs) program, the only other Title III grants that are awarded by formula.

**TRIO:** Retention and support services are vital to achieving the national goal of having the highest proportion of college graduates in the world by 2020. TRIO programs, such as Student Support Services and Upward Bound, were created out of recognition that college access is not enough to ensure advancement and that multiple factors work to prevent the successful completion of postsecondary programs for many low-income and first-generation students and students with disabilities. Therefore, in addition to providing the maximum Pell Grant award level, it is critical that Congress also sustain student assistance programs, such as Student Support Services and Upward Bound so that low-income and minority students have the federal support necessary to allow them to remain enrolled in and ultimately complete their higher education degrees.

**Pell Grants:** The importance of Pell Grants to TCU students cannot be overstated. More than 70 percent of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other sources of financial aid than students at state-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do -- they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of today's highly technical workforce. TCUs are open enrollment institutions. Recent placement tests administered at TCUs to first-time entering students indicated a considerable

need for remedial math, reading, and writing. Clearly, the greatly reduced Pell Grant eligibility limit is a significant barrier to the success of TCU students in completing a postsecondary degree. Students requiring remediation can use as much as a full year of eligibility enhancing their math, and/or reading/writing skills, thereby hampering their future postsecondary degree plans. A prior national goal was to provide access to quality higher education opportunities for all students regardless of economic means, at which TCUs have been extremely successful. While the new national goal intends to produce graduates with postsecondary degrees by 2020, this change in policy does not advance that objective. On the contrary, the change in the regulations will cause many low-income students to once again abandon their dream of a postsecondary degree, as they will simply not have the means to continue to pursue it. This new policy evokes the adage “*penny wise - pound foolish*” and could indeed compromise the laudable goal of producing a well-trained technically savvy workforce. *The TCUs urge the Subcommittee to continue to fund this essential program at the highest possible level, and to direct the Secretary of Education to implement a process to waive the impractical 12 semester Pell Grant eligibility for TCU students, to allow them to catch-up and excel.*

## **II. Perkins Career and Technical Education Programs**

- **Tribally-Controlled Postsecondary Career and Technical Institutions:** Section 117 of the Perkins Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. *AIHEC requests \$8,200,000 to fund grants under Sec. 117 of the Perkins Act.*
- **Native American Career and Technical Education Program (NACTEP):** NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. *The TCUs strongly urge the Subcommittee to continue to*

*support NACTEP, which is vital to the continuation of TCU career and technical education programs that provide job training and certifications to remote reservation communities.*

### **III. American Indian Adult and Basic Education (Office of Vocational and Adult**

**Education)** This program supports adult basic education programs for American Indians offered by state and local education agencies, Indian tribes, agencies, and TCUs. Despite the absence of dedicated funding, TCUs must find a way, often using already insufficient institutional operating funds, to continue to provide adult basic education classes for those American Indians who the present K-12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The new GED exam, which was instituted in January 2014, is more focused on mathematics. As noted earlier, placement tests for TCU-entering students reveal a great need for math remediation. Additionally, the new GED test is fully computerized. While younger GED hopefuls may be well-versed and comfortable with computer-based testing, older and poorer citizens may not be. These factors indicate a further and growing need for adult basic educational programs and GED test preparation on Indian reservations. TCUs must have sufficient and stable funding to continue to provide these essential services and to ensure their respective reservation community residents have the same chances to succeed as others throughout the country. In FY 2015, Congress appropriated approximately \$569,000,000 million for Adult Education State grants. *TCUs request the that \$8,000,000 of the funds appropriated for Adult Education State Grants in FY 2016 be made available for competitive awards among the TCUs to help meet the growing demand for adult basic education and remediation program services on their respective Indian reservations.*



**U.S. DEPARTMENT OF HEALTH and HUMAN SERVICES PROGRAM****Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF):** Tribal

Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are instrumental in meeting the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. In FY 1999 Health and Human Services-Administration for Children and Families established the TCU-Head Start Partnership program. By 2004, TCUs had awarded more than 400 certificates and degrees. The 2007 reauthorization of the Head Start Act included mandates on education for Head Start workers and teachers, and specifically authorized the TCU-IIS Partnership. Ironically, that was the last year of funding for the program. Today, 71 percent of teachers nationally, have required the degrees and credentials. By contrast, in Indian Country (Region 11) only 36 percent of the teachers meet the requirements set forth in the Head Start Act reauthorization. Clearly, there is great need for proper training in Indian Country, and the TCUs are perfectly situated to help address this inexcusable gap in training the tribal Head Start workforce. *The TCUs request that of the over \$10 billion proposed for making payments under the Head Start Act, \$5 million be designated for the TCU-Head Start Partnership program, as reauthorized in PL 110-134, to ensure that TCUs can continue to provide high quality, culturally appropriate training for those working in reservation Head Start programs.*

We respectfully request that the Members of the Subcommittee continue and expand the federal investment in the nation's Tribal Colleges and Universities and carefully consider our FY 2016 appropriations needs and requests.



To: House Appropriations Committee

Outside Witness Testimony from: William Smith, Executive Director, National Coalition of STD Directors

CDC's Division of STD Prevention Funding History

FY2016 Recommendation*:	\$212 million*
FY 2016 President's Budget:	\$157.3 million
FY2015 Funding Level:	\$157.3 million
FY2014 Funding Level:	\$157.7 million
FY2013 Funding Level:	\$154.9 million
FY2012 Funding Level:	\$163 million

*\*\$54.7 million increase*

On behalf of the members of the National Coalition of STD Directors (NCSD), I am writing to request an additional \$54.7 million for the Division of STD Prevention in fiscal year (FY) 2016 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral

Hepatitis, STD and TB Prevention at the CDC. NCSD members represent sexually transmitted disease (STD) programs in all fifty states, seven cities and eight U.S. territories.

STDs remain major epidemics in the United States. Each year, there are almost 20 million new cases of STDs, approximately half of which go undiagnosed and untreated. These new STDs cost the U.S. health care system \$16 billion every year—and cost individuals even more in immediate and life-long health consequences, including infertility, higher risk of acquiring HIV, and certain cancers. In addition, having other STDs increases the likelihood of contracting HIV, and in turn, having HIV also increases the likelihood of contracting and spreading STDs. Investments in STD prevention and treatment further the National HIV/AIDS Strategy's goal of reducing new HIV infections.

The CDC's Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs and invests most of its resources in state, territorial, and large city health

departments. In fiscal year 2016 funding, please support an increase of \$54.7 million to support the prevention of STDs and their complications and to ensure those on the front lines of STD prevention have funding to prepare for the emerging threat of drug-resistant gonorrhea, respond to the rising rates of syphilis, and other outbreaks.

The current public health infrastructure has been continually strained by budget reductions both at the federal and state level and is currently unable to prepare as necessary for the arrival of untreatable gonorrhea as well as responding to growing epidemics and the needs of diverse populations. STD programs have been doing more with less for years and it can no longer continue. The system cannot respond to additional demands and threats with the same level of funding; additional funding is desperately needed.

**Gonorrhea Resistance: \$33.98 million**

Gonorrhea is the second most commonly reported communicable disease in the United States. Gonorrhea has developed resistance to every class of antibiotics recommended for its treatment; we are now on our last line of defense to treat this disease that is a major cause of pelvic inflammatory disease, ectopic pregnancy, infertility and can facilitate HIV transmission.

In 2013, the CDC released Antibiotic Resistance Threats in the United States, 2013, its first-ever snapshot of the burden and threats posed by the antibiotic-resistant germs having the most impact on human health and in this report named drug-resistant gonorrhea one of three “urgent” threats, the highest level in this report. If drug-resistant gonorrhea becomes widespread not only would it dramatically increase gonorrhea rates, the broader public health impact during a 10-year period would be devastating. The direct medical costs of drug-resistant gonorrhea are estimated to be \$235 million 10 years after onset of drug resistance. In reality, however, the real costs of gonorrhea resistance are likely to be much higher—this estimate does not account for increased

susceptibility monitoring, additional provider education, case management, and the need for additional courses of antibiotics and follow-up. The best way to address growing gonorrhea resistance now, before its arrival on our shores, is to decrease the disease burden of gonorrhea.

Overall gonorrhea rates were stable from 2012 to 2013; however, for the first time since 2000, the rate of reported gonorrhea cases among men was higher than the rate among women. In fact, during 2009–2013, the gonorrhea rate among men increased 20.3 percent while the rate among women decreased two percent. Regional differences also exist; during 2012–2013, the rate of reported gonorrhea cases in the Western United States, where gonorrhea resistance has been the highest, increased among both men (17.3 percent) and among women (11.8 percent). The most salient example is a startling 393 percent increase in gonorrhea cases in Utah in the last four years.

This request outlines what state and local health departments, as well as on-the-ground partners, need to effectively respond to the growing resistance of gonorrhea to the last drug shown to treat it. It outlines the needs in four distinct areas:

- **Proper Diagnosis and Treatment:** Scaled up screening programs are needed, as well as ensuring the recently-updated CDC screening and treatment guidelines for gonorrhea are being followed by private providers. (\$11.38 million)
- **Surveillance and Increased Lab Capacity:** CDC currently conducts surveillance for gonorrhea resistance through the Gonococcal Isolate Surveillance Project (GISP), a sentinel surveillance that collects data from a group of STD clinics around the country. Using the current GISP system as a model, this funding would ensure we receive not only more gonorrhea resistance data but also data in real time and increase lab capacity across the country. (\$6.1 million)

- Evidence-Based Interventions for Diverse Populations: Funding is need to scale-up existing evidence-based interventions, particularly for populations most at risk, as well as developing additional interventions. (\$10 million)
- Education and Awareness: Additional funding is needed to increase STD education and awareness efforts across the country. The public must be better educated on the reality of the rise of multi-drug resistant gonorrhea and what it means for the current and future treatment of gonorrhea. (\$6.5 million)

### **Increasing Syphilis Rates, Including Congenital Syphilis: \$1.2 million**

Data release by the CDC late last year showed that rates for primary and secondary syphilis, which is the most infectious stages of syphilis, increased by an alarming 10 percent in 2013, the year of most recent data, on top of an 11 percent increase in 2012. The rate of primary and secondary syphilis in 2013 is the highest recorded rate since 1996. Syphilis and HIV co-infection among MSM is very common, with 52 percent of MSM with primary and secondary syphilis co-infected with HIV. This second year of double digit increases of syphilis rates also significantly intersects with our HIV epidemic. Increasing syphilis rates continues to affect populations already disproportionately impacted by all STDs, including HIV, most notably gay men and other men who have sex with men (MSM) and has the potential of stunting any gains we have made in reducing our HIV epidemic.

Congenital syphilis rates also increased 3.6 percent in 2013, the first increase in congenital syphilis since 2008. This disease can cause infant death, developmental delays, and seizures when a pregnant woman has syphilis and it is not treated before delivering.

### **Disease Intervention Specialists: Outbreak Response Workforce: \$19.5 million**

The importance of DIS to controlling disease outbreaks of all kinds cannot be overstated, as evidenced by their key role in the control of Ebola. This workforce infrastructure is vital to responding not only to emergencies such as this, but to contain our STD, including HIV, epidemics across the country. These individuals are the unsung heroes of public health; few have heard of them, but we desperately rely on them when many types of emergencies occur.

This infrastructure is housed in state and federal health departments and is often funded by federal dollars through grants from the Division of STD Prevention at the CDC. The functions of DIS are not going to be fulfilled by the private sector, but will need to be continued to be funded by the discretionary funding appropriated by this Committee.

DIS positions are often low paying and incredibly demanding. That, coupled with reductions in investments in the public health system, has eroded the DIS workforce over time. Additional resources are desperately needed to bolster DIS staffing. Limited funds at both the state and local levels do not allow for DIS to follow up on all of the cases of STDs, including HIV, that are reported annually. Additional funds are desperately needed to allow for more DIS to perform contact tracing to stop the spread of STDs. We need to ensure this workforce continues if we ever hope to control STDs, including HIV, but also so we can adequately and effectively respond to public health emergencies, including Ebola.

To allow for STD public health programs to respond to gonorrhea resistance, increasing syphilis, and prepare for outbreaks of all kinds, please support an increase of \$54.7 million for the Division of STD Prevention in FY2016. For more information about this funding request or STD prevention in general, please contact the National Coalition of STD Director's Director of Policy and Communications, Stephanie Arnold Pang at [sarnold@ncsddc.org](mailto:sarnold@ncsddc.org) or 202-842-4660.

Infectious Diseases Society of America

**Testimony of the Infectious Diseases Society of America (IDSA)  
On the Fiscal Year 2016 Department of Health and Human Services Budget  
Prepared for the House, Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Submitted by Stephen B. Calderwood, MD, FIDSA, IDSA President  
April 29, 2015**

On behalf of the Infectious Diseases Society of America (IDSA), thank you for the opportunity to provide testimony in support of the U.S. Department of Health and Human Services (HHS) agencies and programs that contribute to the prevention, detection and treatment of infectious diseases (ID). IDSA represents more than 10,000 ID physicians and scientists devoted to patient care, prevention, public health, education, and research. IDSA recommends increased Fiscal Year (FY) 2016 federal investments in public health and biomedical research to save lives, contain health care costs, and promote economic growth. More specifically, IDSA encourages the Subcommittee to provide a program level of \$7.8 billion for the Centers for Disease Control and Prevention (CDC) as well as at least \$32 billion for the National Institutes of Health (NIH).

IDSA is particularly supportive of initiatives contained in the President's Budget Request (PBR) for FY 2016 to address the growing public health crisis of antibiotic resistance. These proposals enable implementation of the recently released National Action Plan for Combating Antibiotic-Resistant Bacteria (CARB). The Action Plan reflects recommendations put forward by the President's Council of Advisors on Science and Technology (PCAST) in their September 2014 Report to the President on Combating Antibiotic Resistance. In particular, IDSA urges the Subcommittee to fund the proposed CDC Antibiotic Resistance Solutions Initiative. We ask that the final FY 2016 Labor-HHS-Education appropriations bill also support the role of the National Institutes of Health (NIH) and the Biomedical Advanced Research and Development Authority

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(BARDA) in stimulating research and development (R&D) for rapid ID diagnostics and antibiotics.

## **CENTERS FOR DISEASE CONTROL AND PREVENTION**

The recent outbreak of Ebola virus disease (EVD) in West Africa and subsequent cases in the United States demonstrate that infectious diseases respect no national borders and that the CDC must be appropriately funded to maintain readiness ahead of new crises. IDSA members are partnering with the CDC and other federal agencies to respond to the EVD crisis. We ask that the Subcommittee support collaborations between government, industry, academia and other non-governmental organizations to address the full range of infectious diseases confronting the public. Our country requires a fully engaged and stably supported CDC to address public health needs such as slowing the rise of antibiotic resistance, preventing and treating neglected tropical diseases (NTDs), increasing immunization rates and stopping the spread of HIV.

Conservative estimates indicate that more than two million Americans suffer from antibiotic-resistant infections each year and that approximately 23,000 will die. Additionally, there were half a million *Clostridium difficile* (*C. difficile*) infections in the United States in 2011, and 29,000 died within 30 days of the initial diagnosis. *C. difficile* is a unique bacterial infection that, although not significantly resistant to the drugs used to treat it, is directly related to antibiotic use and resistance. Carbapenem-resistant Enterobacteriaceae (CRE) has been labeled a “nightmare bacteria.” Nearly half of individuals who develop a bloodstream infection from CRE will die. Each year, antibiotic resistance results in an additional 8 million hospital days and costs in excess of \$20 billion to the U.S. health care system. The actual human and financial costs are likely far higher, as our surveillance and data collection capabilities cannot yet



## Infectious Diseases Society of America

capture the full disease burden. The death and financial tolls rise with each day that we fail to act.

PCAST and the CDC have recommended actions in four core areas to address the problem, including prevention, tracking, antibiotic stewardship, and development of new antibiotics and rapid ID diagnostics. The CDC has proposed FY 2016 activities in each of these areas for which new funding is needed.

### **National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)**

The NCEZID leads CDC efforts to address antibiotic resistance. As such, we ask that it be provided at least the \$699 million requested by the Administration, including at least \$264 million for the Antibiotic Resistance Solutions Initiative. This initiative would build prevention programs in all 50 states and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria. The CDC projects that over five years, the initiative will lead to a 60% decline in health-care associated CRE, 50% reduction in *C. difficile*, 50% decline in bloodstream methicillin-resistant *Staphylococcus aureus* (MRSA), 35% decline in health-care associated multidrug-resistant *Pseudomonas* spp., and 25% reduction in multidrug-resistant *Salmonella* infections, more than covering the costs of investing in these programs now.

IDSA also supports the proposed \$14 million increase for the National Healthcare Safety Network (NHSN) to expand the number of participating healthcare facilities to 17,000 and increase the number of sites reporting antibiotic use and antibiotic resistance data. Information provided via NHSN is critical for evaluating the success of interventions designed to reduce

## Infectious Diseases Society of America

inappropriate antibiotic use and limit the development of resistance and is therefore an integral component to broader efforts to address resistance.

IDSA thanks Congress for funding the Advanced Molecular Detection (AMD) initiative in FY 2015 and recommends that at least \$30 million be allocated for it in FY 2016. AMD strengthens CDC's molecular sequencing tools and bioinformatics capacity to more rapidly and accurately detect infectious diseases and resistance. During the most recent Ebola virus disease outbreak, AMD methods were utilized to determine whether the virus was changing as it spread through different populations, which facilitated appropriate responses.

## NATIONAL INSTITUTES OF HEALTH

### National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, we believe that the National Institute of Allergy and Infectious Diseases should be funded at least at \$4.62 billion as requested by the Administration in the FY 2016 PBR. Decreases in the purchasing power of NIAID have limited investment in new research and provided a disincentive for the pursuit of ID research careers so critical to the discovery of new vaccines, antimicrobials, diagnostics, and prevention strategies.

The NIAID is central to pursuits of new rapid ID diagnostics and antibiotics. A recent IDSA report, *Better Tests, Better Care: The Promise of Next Generation Diagnostics* explains that advances in biomedical research over the last few decades create the potential for increasingly simple, fast and reliable diagnostic tests for infectious diseases. By allowing physicians to quickly distinguish between bacterial and viral infections, better diagnostics can lead to faster and more appropriate treatments for patients, help preserve the utility of our existing drugs, and aid in identifying individuals to participate in clinical trials. Last year, NIAID stated its intention to place special emphasis on rapid diagnostics. Several initiatives

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have been announced, such as funding for diagnostics to quickly detect bacteria responsible for drug-resistant infections acquired in hospital settings and tests to identify reservoirs of latent HIV infection.

The NIAID supports the Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco. With sufficient funding, the research network/infrastructure will continue studies to address antibiotic resistance. Severe economic disincentives continue to cause private companies to leave the antibiotics market, making federally funded research in this area more critical than ever.

#### **ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)**

##### **Biomedical Advanced Research and Development Authority (BARDA)**

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. PCAST has identified BARDA as best positioned to elicit private investments necessary to address antibiotic resistance. However, the BARDA budget has been flat for several years, with inflation leading to loss of purchasing power. Increased funding would allow BARDA to work with industry as a counter to current market failures. IDSA recommends that the Subcommittee provide at least the \$522 million requested for BARDA in the president's budget for FY 2016. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on other medical countermeasures to address biothreats.

Once again, thank you for the opportunity to submit this statement on behalf of the nation's ID physicians and scientists. We rely on strong federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Jonathan Nurse at [jnurse@idsociety.org](mailto:jnurse@idsociety.org) or (703) 299-0202.



**WRITTEN TESTIMONY FROM  
DR. IVY TURNBULL, DEPUTY EXECUTIVE DIRECTOR  
AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN, YOUTH & FAMILIES  
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES  
HOUSE COMMITTEE ON APPROPRIATIONS  
APRIL 27, 2015**

Dear Chairman Cole and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record in opposition of the FY 2016 budget proposal consolidating Ryan White Part D funding into Part C and in support of maintaining Part D of the Ryan White Program as part of the FY 2016 Labor, Health and Human Services, Education, and Related Agencies appropriations measure. This testimony also has the support of the Elizabeth Glaser Pediatric AIDS Foundation.

**Ryan White Part D Funding Request**

Sufficient funding of Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with

HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of Ryan White Part D Programs, providing \$75,297,000 million to the program in FY 2015, restoring dedicated funding eliminated in the President's FY 2015 budget proposal. While the AIDS Alliance for Women, Infants, Children, Youth & Families understands that these are difficult economic times, we are requesting the Subcommittee to maintain its commitment to the Ryan White Part D program and again restore its dedicated funding eliminated in the President's FY 2016 budget proposal and increase Ryan White Part D funding by \$9.9 million in FY 2016.

#### **Ryan White Part D Background and History**

Over concerns with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing \$5 million for the Pediatric AIDS Demonstration Projects in the FY 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 and today are known as Ryan White Part D and have served approximately 200,000 women, infants, children, youth and family members. Since the program's inception in 1988, Part D programs have been and continue to be the entry point into medical care for women and youth. The family-centered primary medical and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth. Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and HIV exposed infants, when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs

continue to be instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV- positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the health care needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

In 2012, Part D provided funding to 114 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 states and Puerto Rico. These grantees also provide support services which include case management (medical, non-medical, and family-centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees also receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for two decades.

### **A Response to Women, Infants, Children, and Youth**

While accounting for less than 5 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families. Part D funded programs played a leading role in reducing mother-to-child transmission of HIV-from more than 2,000 newborn

infections annually more than a decade ago to an estimated 187 in 2013 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,000 HIV-positive women giving birth every year in the U. S. that need counseling, services and support to prevent pediatric HIV Infections. According to the CDC, youth aged 13-24 accounted for 26 percent of all new HIV infections in the US in 2010. Most new HIV infections in youth (about 57 percent) occur in young Black gay and bisexual males. Of the new HIV infections among youth, 2,100 are among young women; two-thirds of these are among young Black women. Ryan White Part D programs are the entry point into medical care for many of these HIV positive youth. According to the Health Resources and Services Administration, more than 37 percent of women receiving medical care in Ryan White Programs. Additionally, Part D provides medical and supportive services to a large number of women over 50 who are HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets. Full implementation of the Affordable Care Act (ACA), along with continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

### **Proposed Consolidation**

The medical and supportive services provided by Ryan White Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS and are not currently being provided by other parts of the Ryan White Program, including Ryan White Part C. The proposed consolidation of Part D

funding into Part C in the federal budget would eliminate a strong safety net for our most vulnerable populations. Furthermore, the loss of Part D funds in some community areas would profoundly impact access to comprehensive HIV care and treatment for women, infants, children and youth. Many of the population served by Part D will be lost or never enter into care thus increasing the existing gaps in the HIV Care Continuum. Moreover, major program changes that are this controversial should be left to Congress and should not be done through the appropriations process.

### **Conclusion**

While we recognize the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs , the elimination of dedicated funding for Ryan White Part D in FY 2016, and the proposed Part C/D consolidation would undoubtedly destabilize existing models of care created to address the unique needs of our most vulnerable populations with HIV and jeopardizes the success of retaining these populations in life-saving HIV care and treatment ensuring achieved and maintained viral load suppression. We urge the Committee to reject the President's FY 2016 budget proposal to eliminate dedicated funding for Ryan White Part D and move the funding to Part C, and respectfully request that the Committee include language in the appropriations bill attesting to such. Without the Ryan White Part D program, many of these medically-underserved women, infants, children and youth would not receive the vital primary care and support services provided to them for the last two decades. On behalf to the women, infants, children, and youth living with HIV/AIDS and the 114 Ryan White Part D funded programs across the country that serve them we sincerely thank you for all that you do to ensure that these populations receive the much needed primary care and treatment needed to sustains their lives.



28 April 2015

To: U.S. House of Representatives Committee on Appropriations  
 Subcommittee on Labor, Health & Human Services, Education and Related Agencies

I am writing on behalf of the Boston chapter of the Autistic Self Advocacy Network to support continued appropriations to support Home and Community-Based Services (HCBS) and community integration-related activities, including efforts that would lead to downsizing or closure of institutional or segregated facilities such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), congregate residential facilities, sheltered workshops, or segregated day habilitation programs. These activities may be conducted by any component of HHS, including the Administration on Intellectual and Developmental Disabilities (AIDD), the National Council on Disability (NCD), and the Centers for Medicare & Medicaid Services (CMS). Far from depriving individuals of choice, these efforts help to rebalance public spending toward the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Community integration efforts help bring federal funding for disability-related services into alignment with the 1999 *Olmstead* decision, which requires services to be delivered in the most integrated setting possible. Many people with disabilities who need long-term services and supports continue to be forced into nursing facilities and other institutions against their will because adequate community-based services were not available. Segregated and institutional settings are rife with opportunities for abuse, in addition to being significantly more costly than community-based settings.

An essential component of community integration efforts is enforcement of regulations that ensure that federal funds specifically earmarked for integration are not used to fund institutional or segregated placements. In order to make community-based services available, it is often necessary to rebalance funding toward community-based services as opposed to institutional settings. For example, Congress authorized federal reimbursement to states who provide Home and Community-Based Services through their Medicaid programs. HCBS programs were designed specifically to promote fully integrated service delivery settings in the community—in other words, supporting the self-determination of people with disabilities by providing meaningful choices for where they can live, work, and receive services in their own homes and communities. It is vitally important that HCBS funds are not used for any settings, programs, or types of services that are not truly integrated and based in the community. Inclusion of any language prohibiting use of congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice and force them to live and receive services in restricted and segregated settings instead of the community.

People with disabilities have fought for decades to make meaningful choices about community-based options a reality. We believe that all people should have the right to stay in their own communities, and that it is imperative for the past several decades' move away from institutions to continue. I urge the Appropriations Committee to ensure that HHS is able to continue its vital work on HCBS implementation and community integration. This work will ensure that many more people with disabilities have the opportunity to transition out of unnecessarily restrictive settings and live in fully integrated communities.

Sincerely,

Finn Gardiner  
 Boston Community Coordinator, Autistic Self Advocacy Network  
 Somerville, Massachusetts  
[fgardiner@autisticadvocacy.org](mailto:fgardiner@autisticadvocacy.org)

**Written Testimony for the Record of Dr. Linda Selman  
Member of the Department of Disabilities Services Board  
Parent of Developmentally Disabled Son**

**leselman@saumag.edu**

**870-234-6487**

**Arkadelphia Human Development Center  
Friends, Family and Guardians**

**Submitted to the Senate Appropriations Subcommittee on Labor, Health & Human  
Services, Education and Related Agencies**

As subcommittee lawmakers you have the opportunity to protect my son, his friends, and thousands of other Americans with severe mental disabilities. These most vulnerable citizens live in this country's congregate care facilities (ICFs) which serve people who cannot care for themselves. These facilities provide safety, medical care, employment opportunities, social interaction, and, in short, loving, protective communities for our special-needs children. Unless the federally funded HHS agencies are stopped from using our tax dollars to close these Medicaid inspected facilities, such as the one my son lives in, their lives are in jeopardy. The documented evidence reveals that the closings of these facilities are contrary to federal law and have contributed to the steep rise in mortality rates for our intellectually disabled loved ones.

Please prevent HHS from using our tax-payer dollars to close our children's homes and thereby endanger their safety and, as has happened in many states, their very lives. I have heard something from these HHS groups about our disabled children deserving the "dignity of risk" that comes with living in the wider community. What they do require and deserve are the twenty-four-hour care and constant safe-guarding of a loving, well-trained staff familiar with their special needs. Don't let these groups crucify our vulnerable children on the cross of their ideology.

Anyone interested in my family's personal journey with an autistic, intellectually disabled child may enjoy reading "Frank David's Story" at this site:

<http://www.vor.net/get-involved/great-story-submissions/152-frank-davids-story>

## Written Testimony

### **FY16 Funding: Older Americans Act**

Prepared for presentation to the  
U.S. House Appropriations Subcommittee on  
Labor, Health & Human Services, Education, and Related Agencies

*Submitted By:*

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**April 29, 2015**

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, **Oral Health America (OHA)**, a leading organization dedicated to changing lives by connecting communities with resources to drive access to care, increase health literacy and advocate for policies that improve overall health through better oral health for all Americans, especially those most vulnerable; is requesting FY2016 funding for all programs administered under the **Older Americans Act (OAA)** be restored to at least FY2010 levels. Of particular interest to OHA is to ensure *Title III-D, Disease Prevention and Health Promotion*, is restored to at least \$21,000,000 because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system.

The OAA provides federal programs that serve to meet the needs of millions of older Americans. We understand the United States continues to operate amid a challenging budgetary environment. However, OHA believes that proper federal investment in the OAA is critical to keep pace with the rate of inflation and to meet the needs of this ever-growing segment of the population through the multitude of services the OAA provides. Simply stated, proper investment in OAA saves taxpayer dollars. This is especially evident when it comes to health services. Health services that emphasize prevention and promotion will help to reduce disease, leading to the improvement of the overall health and well-being of America's older adults and resulting in the reduction of premature and costly medical interventions. OHA strongly contends that one's health and overall well-being begins with proper oral health. For all of these reasons, OHA opposes sequestration and urges Congress to find a balanced solution to address deficit reduction.

### **Background**

The population of the United States is aging at an unprecedented rate. Older adults make up one of the fastest growing segments of the American population. In 2009, 39.6 million seniors were U.S. residents. This aging cohort is expected to reach 72.1 million by 2030 -- an increase of 82 percent.<sup>1</sup>

The oral health of older Americans is in a state of decay. The reasons for this are complex. Limited access to dental insurance, affordable dental services, community water fluoridation, and programs that support oral health prevention and education for older

Americans are significant factors that contribute to the unmet dental needs and edentulism among older adults, particularly those most vulnerable. While improvements in oral health across the lifespan have been observed in the last half century, long term concern may be warranted for the 10,000 Americans retiring daily, as it is estimated that only 9.8 percent of this “silver tsunami”—baby boomers turning age 65 -- will have access to dental insurance benefits.<sup>i</sup>

**Dental Health and Disparities:** Oral health data reveals that many older adults experience adverse oral health associated with chronic and systemic health conditions. For example, associations between *heart disease, periodontitis and diabetes have emerged in recent years, as well as oral conditions such as xerostomia associated with the use of prescription drugs.*<sup>iii iv</sup> Xerostomia, commonly known as dry mouth, contributes to the inception and progression of dental caries (cavities). For older Americans, the occurrence or recurrence of dental caries coupled with an inability to access treatment may lead to significant pain and suffering along with other detrimental health effects.

These oral conditions disproportionately affect persons with low income, racial and ethnic minorities, and those who have limited or no access to dental insurance. Older adults with physical and intellectual disabilities and those persons who are homebound or institutionalized are also at greater risk for poor oral health.<sup>v</sup>

As examples of these disparities, older African American adults are 1.88 times more likely than their white counterparts to have periodontitis,<sup>vi</sup> low-income older adults suffer more than twice the rate of gum disease than their more affluent peers (17.49 verses 8.62 respectively); and Americans who live in poverty are 61 percent more likely to have lost all of their teeth when compared to those in higher socioeconomic groups.

**Aging in Place:** Despite these existing conditions, recent dental public health trends demonstrate that as the population at large ages, older Americans are increasingly retaining their natural teeth.<sup>vii</sup> Today, many older adults benefit from healthy aging associated with the retention of their natural teeth, improvements in their ability to chew, and the ability to enjoy a variety of food choices not previously experienced by earlier generations of their peers.

Nearly 90 percent of older adults want to stay in their own homes as they age, often referred to as “Aging in Place.” Today’s older adults are living more independently than previous generations. In fact, only 9 percent of older adults live in a long term care setting. Maintaining a healthy mouth is one of the keys to independence as we age, however resources for oral health remain conspicuously absent from home and community-based services and are largely disconnected and difficult to access.

**Oral Care Provider Issues:** Although a growing number of older Americans need oral healthcare, the current workforce is challenged to meet the needs of older adults. The current dental workforce is aging, and many dental professionals will retire within the next decade. A lack of geriatric specialty programs complicates this problem, and few practitioners are choosing geriatrics as their field of choice.

While these trends are favorable, adverse oral health consequences are emerging. Due to reasons stated in this report, together with increased demand for services, lack of access to dental benefits through Medicare, increased morbidity and mobility among older adults, and reduced income associated with aging and retirement, many older Americans are unable to access oral health care services. As a result, many older adults who have retained their natural teeth are now experiencing dental problems.

### **Older Adults’ Oral Health in State of Decay**

OHA released *State of Decay* on October 8, 2013, which is a state-by-state analysis of oral healthcare delivery and public health factors impacting the oral health of older adults. The report revealed more than half of the country received a “fair” or “poor” assessment when it

comes to minimal standards affecting dental care access for older adults. The top findings of the report were:

- **Persistent lack of oral health coverage across much of the nation.** Forty-two percent of states (21 states) provide either no dental benefits or provide only emergency coverage through adult Medicaid Dental Benefits. Nearly 70% of older Americans lack dental insurance, and in the context of a rapidly aging nation, this percentage will only likely increase.
- **Strained dental health work force.** Thirty-one states (62 percent) have high rates of Dental Health Provider Shortage Areas (HPSAs), meeting only 40 percent or less of dental provider needs.
- **Tooth loss remains a signal of suboptimal oral health.** Eight states had strikingly high rates of edentulism, with West Virginia notably having an adult population that is 33.8 percent edentate.
- **Deficiencies in preventive programs.** Thirteen states (26 percent) have upwards of 60 percent of their residents living in communities without water fluoridation (CWF), despite recognition for 68 years that this public health measure markedly reduces dental caries. Hawaii (89.2 percent) and New Jersey (86.5 percent) represent the highest rates of citizens unprotected by fluoridation, an unnecessary public peril.

Moreover, poor oral health has substantial financial implications. For example, in 2010 alone, between \$867 million and \$2.1 billion was spent on emergency dental procedures.<sup>viii</sup> When compared to care delivered in a dentist's office, hospital treatments are nearly ten times more expensive than the routine care that could have prevented the emergency. This places a costly yet avoidable burden on both the individual and the health institutions that must then bear the expense.

In sum, oral health and access to preventive care significantly impact overall health and expenditure, yet are difficult to maintain—particularly for older adults—in the nation's present context of support systems and healthcare. This fall, OHA will release an update to **State of Decay** and will welcome the opportunity to share its latest findings with the Subcommittee.

### **How OHA Empowers Older Adults to Meet their Oral Health Needs**

Oral Health America's Wisdom Tooth Project® aims to change the lives of older adults especially vulnerable to oral disease. Its goal is to educate Americans about the oral health needs of older adults, connect older adults to local resources, and to advocate for policies that will improve the oral health of older adults. The Wisdom Tooth Project achieves these goals through five strategies: publications, our web portal, regional symposia, communications, and demonstration projects.



In addition to the ***State of Decay*** report referenced above, a vital component of the Wisdom Tooth Project is Toothwisdom.org, which is a first-of-its-kind website created to connect older adults and their caregivers to local care and education around the oral health issues they face, the importance of continuing prevention as we age, and the overall impact of oral health on overall health.

### **Importance of OAA Reauthorization to Oral Health of Older Adults**

Recognizing this current state of oral health among older adults, Oral Health America welcomes the bipartisan-supported Older Americans Act reauthorization in the U.S. Senate, S.192. The Senate's bill includes—for the first time—a small provision that allows the Aging Network to use funds they receive for disease prevention and health promotion activities to conduct oral health screenings. Preventive dental care that can be provided through oral health screenings can head off more expensive dental work and help prevent severe diseases. Unfortunately, dentists see older adults everyday living with infection and pain that could be easily avoided with proper care that these screenings could provide. Although the oral health screenings provision would not require new or additional funding under Title III-D, Disease Prevention and Health Promotion Services, restoring funding to at least FY2010 levels would greatly assist the Aging Network to conduct the screenings. More succinctly, the Senate's bill recognizes the importance of oral health and its role in disease prevention. We view this as a step toward improving the oral—and overall—health of older adults and call for the bill's passage.

### **RECOMMENDATION**

It is evident the United States' health care system is woefully unprepared to meet the oral health challenges of a burgeoning population of older adults with special needs, chronic disease complications, and a growing inability to access and pay for dental services. However, the benefits of proper oral hygiene and routine care for older adults to our nation's healthcare system and economy are also quite clear. Through OHA's Wisdom Tooth Project, OHA aspires to change the lives of older adults especially vulnerable to oral disease. OHA views proper funding of the Older Americans Act as a crucial federal investment vehicle to advance health promotion and disease prevention. Therefore, OHA recommends the Subcommittee to restore FY2016 funding for all OAA programs to at least FY2010 levels, and moreover, to ensure *Title III-D, Disease Prevention and Health Promotion*, is restored to at least \$21,000,000 because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system.

Thank you for the opportunity to present and submit our written testimony before the Subcommittee.

<sup>1</sup> Administration on Aging. (2013). *Aging Statistics*. Retrieved from [http://www.aoa.gov/Aging\\_Statistics/](http://www.aoa.gov/Aging_Statistics/)

<sup>2</sup> Consumer Survey, National Association of Dental Plans. 2012.

<sup>3</sup> Ira B. Lamster, DDS, MMSc, Evanthia Lalla, DDS, MS, Wenche S. Borgnakke, DDS, PhD and George W. Taylor, DMD, DrPH. (2008). Journal of the American Dental Association.

<sup>4</sup> Fox, Philip C. (2008). *Xerostomia: Recognition and Management*. Retrieved from:

[http://www.colgateprofessional.com.hk/Leadership/HK/ProfessionalEducation/Articles/Resources/profed\\_art\\_access-supplement-2008-xerostomia.pdf](http://www.colgateprofessional.com.hk/Leadership/HK/ProfessionalEducation/Articles/Resources/profed_art_access-supplement-2008-xerostomia.pdf)

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<sup>v</sup> U.S. Department of Health and Human Services. (2000). *Oral Health in America: A Report of the Surgeon General*. Retrieved from [http://silk.nih.gov/public/hck1ocv\\_@www.surgeon.fullrpt.pdf](http://silk.nih.gov/public/hck1ocv_@www.surgeon.fullrpt.pdf)

<sup>vi</sup> Borrel, L.N., Burt, B.A., & Taylor, G.W. (2005, October). Prevalence and Trends in Periodontitis in the USA: from the NHANES III to the NHANES, 1988 to 2000. *Journal of Dental Research*, 84(10). Retrieved from <http://jdr.sagepub.com/content/84/10/924.abstract>

<sup>vii</sup> Dolan, T. A., Atchison, K., & Huynh, T. N. (2005). Access to Dental Care Among Older Adults in the United States. *Journal of Dental Education*, 69(9), 961-974. Retrieved from <http://www.jdentaled.org/content/69/9/961.long>

<sup>viii</sup> Wall, Thomas and Nasseh, Dr. Kamyar, "Dental-Related Emergency Department Visits on the Increase in the United States," Health Policy Institute, ADA, May 2013, [http://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIBrief\\_0513\\_1.aspx](http://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0513_1.aspx)



## Written Testimony

### FY16 Funding: National Institute for Dental and Craniofacial Research

Prepared for presentation to the U.S. House  
Appropriations Subcommittee on  
Labor, Health & Human Services, Education, and Related Agencies

*Submitted By:*

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President

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**April 29, 2015**

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, the members of the **Friends of the National Institute of Dental and Craniofacial Research (FNIDCR)**, a leading broad-based consortium of individuals, academic institutions, patient advocate groups, dental societies, and corporations, that understands the importance of dental, oral and craniofacial health to our society, are requesting FY2016 funding under section 301 and Title IV of the Public Health Service Act for the **National Institute of Dental and Craniofacial Research (NIDCR)** to be appropriated at **\$425 million**. In addition, FNIDCR recommends funding for the **National Institutes of Health (NIH)** to be appropriated **at least at \$32 billion**. Furthermore, FNIDCR requests Congress to take action to find a solution to end sequestration, and instead, invest in American innovation.

The FY2015 level enacted by the omnibus bill is \$399.88 million for NIDCR. After transfers, NIDCR's total amount for obligation in FY2015 is \$397.7 million. President Barack Obama's FY2016 budget proposal for NIDCR, \$406.7 million, is a welcomed \$9.046 million increase. However, at \$406.7 million, NIDCR still would not be able to keep up with the increasing rate of medical inflation. Nor would this funding level do much to reverse the significant decrease in the number of NIDCR grants awarded, which as a result of a steady decline in purchasing power since 2004, reached its lowest level in 14 years.

#### **Background**

Since 2004, NIDCR's has lost 25% of its purchasing power. In addition, from 1998 to 2011, NIDCR's percentage of total NIH funding decreased from 1.53% to 1.33%, its lowest percentage, *amid a period when NIH's budget doubled*. Save for a slight bump in 2012, this percentage remains at 1.33%. The Friends of NIDCR has been working to reverse this troublesome trend—and return NIDCR research to a percentage of total NIH funding that is more appropriate and proper. For FY2015, NIDCR's percentage of total NIH funding was 1.33%.

- If Congress enacts the president's FY2016 budget figures for NIH (\$31.3 billion) and NIDCR (\$406.7 million), then NIDCR's percentage of total NIH funding would be at an all-time low, 1.30%.

The Friends of NIDCR would welcome the opportunity to work with members of this Subcommittee to ensure NIDCR funding realizes the recommended funding level of \$425 million that, if achieved, will be a step in the right direction to help NIDCR begin to keep up with medical inflation, boost its purchasing power, and increase the number of grants it awards. The latter would provide promise and hope to new and young researchers looking for an opportunity to contribute to the field.

### **NIDCR: A Renown Leader in Research**

For nearly 67 years, NIDCR has been the leading sponsor of research and research training in biomedical and behavioral sciences. Its mission is to *"improve dental, oral and craniofacial health through research and research training, and by sharing science-based health information with the public and health care professionals."*

NIDCR meets its mission by:

- utilizing the latest molecular and genetic tools to **conduct research** on the full spectrum of topics related to craniofacial, oral, and dental health and disease;
- supporting **training and career development programs** for everyone from high school students to independent scientists;
- **sharing research findings** with the public, health care professionals, and policy makers while also producing and distributing **health education materials** for consumers as well as dentists, physicians, and other health care providers.

In addition, NIDCR's Gold Standard Peer Review System ensures that taxpayers' dollars are being utilized in a wise, effective and productive manner.

### **NIDCR Research Benefits All Americans**

Proper federal funding of NIDCR will transform the future of medical and dental practice to the benefit of our society and ease the burden on our nation's healthcare system. Moreover, government investment in oral health research saved Americans \$3 for every \$1 invested.<sup>1</sup> Examples of where NIDCR research has or will benefit society are:

**Tooth Decay:** Fluorides and sealants have cut the rate of the number of American adults, aged 45 and older, who are without teeth by more than half since the 1950s. Through research, new technologies will be developed to further help prevent tooth decay. For example, the bacteria that cause tooth decay live in complex communities called biofilms. By jamming the ability for the bacteria to communicate with one another with the biofilm, it may be possible to disrupt the biofilm and end the threat of tooth decay.

**Oral Cancer Detection:** Oral cancer affects approximately 36,500 Americans each year and approximately 22 Americans die each day from it. Survival rates are among the lowest of all the major cancers. It is difficult to detect and hard to predict its outcome. However, if detected in early stages, the five-year survival rate for those with localized disease is 83 percent. NIDCR-supported research has yielded initial success with developing new diagnostic techniques that can lead to early detection and life-saving interventions. For example, oral cancer is the first cancer to have its biomarkers mapped using Salivary Diagnostics and the presence of these biomarkers resulted in an early diagnosis of oral cancer 93 percent of the time. Furthermore, as a testament to scientific discoveries, oral researchers have confirmed that oral cancer (traditionally thought of as being driven by

<sup>1</sup> <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=129>

extensive use of tobacco and alcohol) possesses a strong and growing link to Human Papilloma Virus (HPV). HPV is now the cause of more oral cancers than smoking. NIDCR supports research aimed to gain a clearer take on HPV-related oral cancers, including their incidence, risk factors, natural history and biology.

**Oral and Craniofacial Biology/Cleft Lip and/or Cleft Palate.** Scientists are defining the genetics that underlie the formation of the head and skull, and researchers are identifying the key areas for craniofacial malformations. For example, NIDCR-supported research has detected proteins associated with craniosynostosis, which is the premature fusion of a baby's skull bones that causes asymmetric skull growth. Moreover, NIDCR researchers are gaining a better understanding of craniofacial disorders such as cleft lip and cleft palate. NIDCR believes this research, which comes under the Translational Genetics and Genomics program, could provide the foundation for the development of early detection methods and more effective treatments.

**Tissue Regeneration.** Researchers funded by the NIDCR are working to engineer and test artificial salivary glands. Studies in animals have demonstrated that artificial salivary glands can last over time after they have been implanted. The aim of researchers in preclinical studies is for the ability of a patient to produce saliva from an artificial salivary gland that has been created from that patient's own salivary gland cells.

**Precision Health Care.** NIDCR is committed to being on the leading edge of personalized and precision health care. According to NIDCR's 2014-2019 Strategic Plan, "NIDCR will continue its support of research toward the development of user-focused, point-of-care technologies that detect dental, oral, and craniofacial health problems in a range of diverse settings, including underserved, low-resource communities."<sup>2</sup> We are excited about the promise of precision or personalized health care and not just for the effective treatment of head or neck cancers. As NIH Director Dr. Francis Collins stated before this Subcommittee on March 3, 2015, a component of precision medicine will be a long-term effort to study a million Americans for virtually all diseases or common conditions, including "periodontal disease and dental caries."<sup>3</sup>

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease,
- Chronic Dry Mouth, and
- Chronic Facial and Oral Pain, such as TMJD.

### **How NIDCR Research Makes a Difference**

Because Friends of NIDCR is a broad-based coalition of members, we are able to share first-hand perspectives from across the spectrum of the oral health community.

#### ***The TMJ Association:***

"During the past decade, NIDCR-funded research directed toward Temporomandibular Disorders has been a "game changer." Previously thought to be a condition about teeth and jaws, research has demonstrated that this is a complex condition mediated by genes, sex, age, and epigenetics. We now also know that for

<sup>2</sup>[http://www.nidcr.nih.gov/research/ResearchPriorities/StrategicPlan/StrategicPlan14/goal2.htm?\\_ga=1.6985458.1331137276.1422370073](http://www.nidcr.nih.gov/research/ResearchPriorities/StrategicPlan/StrategicPlan14/goal2.htm?_ga=1.6985458.1331137276.1422370073)

<sup>3</sup> House Appropriations Subcommittee on Labor, Health & Human Services, Education, and Related Agencies FY16 Budget Hearing on NIH, March 3, 2015, <https://www.youtube.com/watch?v=owAfh1s4RWI&feature=youtu.be>

many, TMD is a chronic pain condition and that in addition these patients also present with other comorbid pain conditions that co-occur more than by chance. These findings have truly revolutionized the way that these conditions are researched and will ultimately be treated. It is important to note that the National Institutes of Health are the only sources of funding of TM Disorders in the United States. We rely on their resources to improve the health care and quality of life for the 35 million TMJ patients in this country. Our hope is in science and the NIH, through its Institutes such as NIDCR, provides us with that hope. This is only the beginning. We're not there yet."

***The American Chronic Pain Association:***

"For many decades, pain has not been recognized as a clinical issue in its own right; it has been seen as a symptom or side effect of other diagnoses. But pain has a huge medical, economic, and social impact. It can delay healing, drive up the cost of care, lead to loss of productivity and disability, and erode quality of life for those afflicted. The NIDCR has led the way in treating pain as a condition worthy of attention. NIDCR research has been forward-looking and comprehensive in its understanding of pain and has offered hope to millions who so often find their concerns overlooked in the scientific community. We urge you to fully fund the NIDCR so that its significant work can continue."

***The University of Alabama at Birmingham School of Dentistry:***

"The UAB SOD is dedicated to leading oral health care through educating dental clinicians and scientists, strengthening our nationally top-ranked research program, and expanding patient-centered clinical practice. We are proud that our dental school is the headquarters for the NIDCR-supported National Dental Practice-Based Research Network, fostering evidence-based dental research through 5,600 total dentists, hygienists, and non-practitioners. A key goal for the SOD is to generate new knowledge at the bench top and to improve care in both the academic clinical and practice-based settings, and to improve overall public health in the community-based setting. Our research programmatic themes include Oral Infection/Immunology, Biomaterials Science/Biomimetic, Craniofacial Development/Genetics, and Implementation Science/Clinical Outcomes Research. As an institution, we are deeply committed to training the next generation of dental academicians and scientists through our NIDCR-supported Dental Academic Research Training (DART) T90 program and several college pipeline honors research programs. The SOD houses the UAB Global Center for Craniofacial, Oral, and Dental Disorders which provides an interdisciplinary and multidisciplinary integrated forum for the diagnosis, treatment, and training related to craniofacial, oral, and dental disorders including oral cancer, periodontal disease, and caries."

**Research Drives the Economy, Innovates**

Despite the fact 54% of Americans thought federal spending for medical and health research should be exempt from across-the-board cuts outlined in the Budget Control Act of 2011<sup>4</sup>, the ramifications of sequestration linger and await again on the horizon for FY16. However, Friends of NIDCR maintains that investment in medical research powers our innovation economy and provides life-saving treatments and cures. For example:

<sup>4</sup> "More than Half of Americans Doubt U.S. Global Leadership in 2020," Research!America press release, March 14, 2012, [http://www.researchamerica.org/release\\_14march12\\_poll](http://www.researchamerica.org/release_14march12_poll)

- a typical NIH grant supports the salaries of about seven high-tech jobs, and
- it is estimated that for every \$1 invested in NIH \$2.21 in local economic growth is generated<sup>5</sup>.

Moreover, cuts or stagnate funding will only set the U.S. back at a time when other countries are rapidly increasing investment in research. Eighty-five percent of likely voters are concerned about the impact of a decreased federal investment in research, including the possibility of scientists leaving their profession or moving abroad to countries with a stronger investment in research.<sup>6</sup> NIDCR-funded grants contribute to our nation's economy and keep scientists from looking abroad for work. FY2014 NIDCR-funded grants had a presence in 133 congressional districts (often multiple awards for a congressional district) in 44 states and territories. This equates to 75 percent of NIDCR-funded research being distributed to grantees at universities, dental schools, and medical schools, primarily in the U.S. Therefore, a significant portion of NIDCR-funded research occurs away from the NIH campus. However, this nationwide NIDCR presence will surely decline with decreased investment in research.

### **Oral Health Disparities**

Finally, the reduction of oral health disparities is one of four goals the NIDCR articulated in its 2014-2019 Strategic Plan. Community-based studies aimed to reduce and eliminate oral health disparities are part of NIDCR's clinical research. For example, in FY 2015, two new funding opportunities were released encouraging research that establishes interventions to reduce or eliminate oral health disparities and inequalities in vulnerable U.S. children. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007. Moreover, NIDCR is striving to improve its ability to share knowledge about the prevention and treatment of disease to people and communities who need it the most. This need is demonstrated from findings from the NIDCR-funded Center for Native Oral Health Research at the University of Colorado.

### **RECOMMENDATION**

Eighty-five percent of Americans are concerned about stagnate funding for medical research.<sup>7</sup> Proper funding of medical and health research is essential to the overall health and well-being of our fellow Americans. We firmly contend that medical discoveries and advances from NIDCR funding lead to improvements in dental practices and change the scope of public health policies across the nation. Whether it is detecting a clear link between bacteria in the mouth and heart disease—or discovering early stages of oral cancer—or searching for breakthroughs to help combat facial and oral pain—we all benefit when we make NIDCR a priority.

**Therefore, based upon the merits of the research conducted by NIDCR, and its demonstrated benefits to the lives of countless Americans, we respectfully request the Subcommittee to fund NIDCR at \$425 million, and NIH at least \$32 billion, so that they can realize their full potential of their worthy missions and sustain its beneficial scientific research.** In addition, Congress must act to find a solution to end sequestration.

Thank you for the opportunity to present our written testimony before the Subcommittee.

<sup>5</sup> <http://nih.gov/about/impact/economy.htm>

<sup>6</sup> "More than Half of Americans Doubt U.S. Global Leadership in 2020," Research!America press release, March 14, 2012.

[http://www.researchamerica.org/release\\_14march12\\_poll](http://www.researchamerica.org/release_14march12_poll)

<sup>7</sup> "America Speaks," Poll Data Summary Volume 13, Research!America, <http://www.researchamerica.org/uploads/AmericaSpeaksV13.pdf>



Center for Independent Living

Audrey Schremmer

Executive Director

Three Rivers Inc.

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS budget for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$306 million for the Independent Living line item in FY 2016.

Three Rivers Inc. is a cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. Three Rivers, like all CILs is unique in that we are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 356 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and the newly added transition services. From 2012-2014, CILs provided the four core service to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals.

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visit our website at: [www.threeriversinc.org](http://www.threeriversinc.org)

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Transition services were added as a fifth core service with the passage of the Workforce Innovation and Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities. This past year, Three Rivers helped 13 individuals transition from a Medicaid funded nursing home placement to a Home and Community Based Services program which resulted in an annual savings of more than 280,000. Yet Three Rivers receives less than \$40,000 in Federal funds each year. Clearly with adequate funding, many more critical needs could be addressed.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2015, the Independent Living Program is receiving nearly \$3 million less in funding than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how

3Rivers Inc.

Center for Independent Living

they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Thank you for your consideration.

Audrey Schremmer, Executive Director



**Person Submitting Testimony:** Jeff Edwards, Director, KY Protection & Advocacy

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [L.H.Approp@mail.house.gov](mailto:L.H.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of Kentucky P&A, the Protection and Advocacy (P&A) agency for Kentucky on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, Kentucky served 233 individual clients, held 41 trainings with 896 people trained, and provided informational and referral services to an additional 651 people. In addition to these activities, 874,000 people were impacted by the activities undertaken by Kentucky

P&A on behalf of groups of clients. These activities benefited individuals in every state and territory in the United States.

As an example of the work done by Kentucky concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

### **Bratcher Decision:**

The Kentucky Court of Appeals in Commonwealth of Kentucky, *Cabinet for Health and Family Services (CHFS) v. Bratcher* affirmed the Franklin Circuit Court's ruling that persons with developmental disabilities who have IQs higher than 70 can qualify from the Supports for Community Living (SCL) home and community based Medicaid waiver. SCL provides an array of services like day programs and respite which help people with intellectual or developmental disabilities avoid institutionalization and live in the community.

Mr. Bratcher suffered a stroke at the age of 15. He currently relies on SCL services to keep him in the home he shares with his nonagenarian mother. He began receiving SCL in 2005 and every year thereafter until 2011 when CHFS decided to de-certify him. CHFS said that because Mr. Bratcher's IQ was above 70 he could not qualify for SCL. On behalf of Mr. Bratcher Kentucky P&A appealed the decision to the Franklin Circuit Court arguing that SCL recipients who have developmental disabilities and an IQ above 70 could qualify for SCL. The Franklin Circuit Court agreed and ruled that CHFS could not graft the intellectual

disability definition—that requires a 70 or below IQ—onto the developmental disability definition.

CHFS then asked the Court of Appeals to review the decision. The Court of Appeals agreed with the Circuit Court's ruling and adopted most of the decision as its own. The Court of Appeals, quoting the Circuit Court, held that "The Cabinet exceeded its statutory powers by grafting the regulation's mental retardation IQ requirement onto the definition of developmental disability. There is no properly promulgated regulation which requires an individual who qualifies for the SCL Waiver on the basis of developmental disability to show first that he also meets the regulation's definition of mental retardation." The Court of Appeals designated the *Bratcher* decision for publication.

#### **Individual Case:**

##### **JC:**

JC is a young man in his thirties. He has a developmental disability and was institutionalized at a state psychiatric hospital for over a year when Kentucky P&A began to advocate on his behalf. Kentucky P&A requested evaluations to determine whether JC was eligible for the Supports for Community Living (SCL) Medicaid Waiver which is a community based with an array of services for persons with intellectual disabilities to prevent institutionalization. JC was denied SCL and Kentucky P&A filed an administrative appeal on his behalf. During the appeal process JC was hospitalized in a psychiatric facility, discharged to a homeless shelter and then to an unlicensed, unregulated facility which P&A was investigating under its authority as authorized by P&A's federal authority. JC also went to jail on misdemeanor charges where Kentucky P&A provided technical assistance to his public defender to have

him transferred to a medical hospital for treatment because he was catatonic. After this hospitalization, JC won his appeal and was granted an emergency slot for Medicaid waiver services. JC is now living in the community in a home and receiving intensive services and has avoided being institutionalized.

**BH:**

BH is a 5 year-old boy diagnosed with autism. He does not like loud noises or crowds. BH's parents placed him in an out-of-state facility after being told by school officials that they would lose custody if they refused. The facility threatened BH's parents with loss of custody due to their objections to medication they felt were unnecessary. Kentucky P&A provided representation and advocated for BH to be discharged from the hospital by working with Kentucky's Department of Community Based Services and school officials and also advising parents about the law and their legal rights. BH only spent three to four days at the facility before coming home and he remains in his parent's custody and out of an institution.

**LC:**

LC is a 76 year-old man with a diagnosis of a developmental disability. He was living at a personal care home, considered to be institutional living in Kentucky, at the time P&A met him. Through advocacy, Kentucky P&A arranged for appropriate assessments to be completed to document his diagnosis to be used to apply for a Medicaid waiver to live in the community in a less restrictive environment. Kentucky P&A worked closely with the state guardianship office, including the commissioner, to complete and submit the application. He was successful in obtaining a Medicaid waiver slot and now lives in the community and has

not been re-institutionalized. It is believed he had been institutionalized the majority of his life.

Thank you for this opportunity to submit this testimony.

**Testimony Prepared for the House Subcommittee on Labor, Health and Human Services,  
and Education and Related Agencies**

***Fiscal Year 2016 Appropriations for the Health Resources and Services Administration's***

***Title VII Health Professions Program***

**Submitted for the Record by the American Academy of Physician Assistants**

**April 29, 2015**

Contact: Sandy Harding, MSW, Senior Director, Federal Advocacy

[sharding@aapa.org/\(571\)319-4338](mailto:sharding@aapa.org/(571)319-4338)

On behalf of more than 100,000 nationally certified physician assistants (PAs), the American Academy of Physician Assistants (AAPA) is pleased to submit comments on the Fiscal Year 2016 appropriation for PA educational programs authorized under Title VII of the Public Health Service (PHS) Act and administered by the Health Resources and Services Administration (HRSA). **AAPA respectfully requests that the House Subcommittee on Labor, Health and Human Services, and Education and Related Agencies approve continued funding of \$280 million for the Title VII health professions education program and provide \$12 million of the funding allocated to the Primary Care Training and Enhancement (PCTE) program for PA education programs.** These amounts are consistent with the requests submitted by the Health Professions and Nursing Education Coalition (HPNEC) and the Physician Assistant Education Association (PAEA). AAPA also urges the Subcommittee to provide continued, full funding for the National Health Service Corps (NHSC) and community health centers (CHCs) as included in H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015.

**Overview of PA Practice:**

PAs are healthcare providers who are nationally certified and state licensed to practice medicine and prescribe medication in every medical and surgical specialty and setting. PAs practice and

prescribe in all 50 states, the District of Columbia, and in all U.S. territories with the exception of Puerto Rico. PAs manage the full scope of patient care, often handling patients with multiple comorbidities. In their normal course of work, PAs conduct physical exams, assist in surgery, diagnose and treat illnesses, order and interpret tests, and counsel on preventative healthcare. As such, PAs are a valuable part of the healthcare team, and they are necessary to ensure the success of the healthcare delivery system as a whole.

### **Overview of PA Education:**

There are currently 196 accredited PA educational programs in the U.S., all of which are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant, and the overwhelming majority of PA programs offer a master's degree in PA studies.

The typical PA student has a bachelor's degree and four years of healthcare experience prior to beginning a PA program. The curriculum generally consists of 26 months of instruction, which includes 400 hours of basic sciences and nearly 1,600 hours of clinical medicine. Students' clinical education is often divided between primary care medicine – family medicine, internal medicine, pediatrics, and obstetrics and gynecology – and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. Once a PA has graduated, he or she must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants and become licensed by the state in which they will practice. PAs must also log 100 hours of continuing medical education every two years and take a recertification exam every ten years.

**PAs and Title VII Funding:**

Title VII of the PHS Act is the only continuing federal funding which is available to PA educational programs. As a result, AAPA supports allocating \$12 million specifically for these programs, which are funded within PCTE. In the 2013-2014 academic year, PA education grants made through PCTE via the Physician Assistant Training in Primary Care program supported the education of 4,071 PA students. Of that number, nearly half were minorities and/or from disadvantaged backgrounds. More than half of the institutions which were awarded grant funds through this program were focused on primary care, and most of them were located in rural and/or medically underserved areas. At the same time, the Expansion of Physician Assistant Training (EPAT) program under PCTE assisted 429 PA students, 120 of whom graduated at the end of the 2013-2014 academic year. Over 50% of these graduates planned to practice in a rural or medically underserved area, and a similar number planned to work in a primary care setting.

In addition to creating more opportunities for PA students to pursue their education, Title VII funding has helped PA programs expand clinical rotations in rural and medically underserved areas. This expansion has benefited local residents who previously had limited access to care while exposing PA students to diverse clinical environments. In many cases, new PAs will choose to remain in the area in which they completed their education. In fact, a review of PA graduates from 1990-2009 showed that PAs who graduated from programs supported by Title VII were 47% more likely to work in rural health clinics than graduates of other programs. As such, continued funding of PA educational programs under Title VII is a win-win scenario for underserved communities and for the nation's healthcare workforce.



**PAs in Primary Care:**

Of the more than 100,000 PAs currently practicing in the U.S., more than 30% work in primary care settings. PAs are one of three primary care providers who may participate in the NHSC, which provides loan forgiveness and scholarship awards to more than 10,000 healthcare professionals who commit to serving for two years in medically underserved areas. Additionally, PAs provide medical care in community health centers (CHCs), and in some cases, serve as CHC directors. CHCs provide cost-effective healthcare throughout the country and serve as medical homes for millions of patients who live in medically underserved areas. CHCs provide a wide variety of healthcare services through team-based care, providing high quality healthcare to CHC patients and significantly reducing medical expenses. AAPA was pleased that funding was approved for both NHSC and CHCs as part of H.R. 2, the Medicare Access and CHIP Reauthorization Act. In keeping with that language, **AAPA strongly supports continued funding of both of these programs.**

**Summary:**

According to a HRSA study released in November 2013, increased use of PAs along with nurse practitioners could help to alleviate the projected shortage of physicians (20,400 by 2020), reducing this need to only 6,400 primary care providers. As a result, strong federal support for PA education programs is necessary to ensure that all Americans have access to high quality healthcare.

AAPA appreciates the opportunity to present our views on the FY16 appropriations for Title VII. We appreciate Congress's past support of Title VII programs, and we look forward to continuing to work with the Subcommittee to this end.



## DISABILITIES LAW PROGRAM

COMMUNITY LEGAL AID SOCIETY, INC.

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**Person Submitting Testimony:** Brian J. Hartman, Project Director, Disabilities Law  
Program, Community Legal Aid Society, Inc., 100 W. Tenth St., Wilmington, DE 19801.

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human  
Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony  
for the record)

I write today to submit testimony for the record demonstrating the work of the  
Community Legal Aid Society, Inc., the Protection and Advocacy (P&A) agency for  
Delaware, on community integration and ensuring access to services for people with  
intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for  
Individuals with Developmental Disabilities (PADD) program have been working to  
ensure that individuals with intellectual and developmental disabilities are free from  
abuse and neglect (both in institutional settings and the community) and that their rights  
and desires are respected and considered as decisions are made concerning

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KENT COUNTY  
SUSSEX COUNTY

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DELAWARE'S PROTECTION AND ADVOCACY SYSTEM FOR PERSONS WITH DISABILITIES

education, employment, housing, and health care. The Delaware P&A is a minimum allotment grantee (\$362,881) under the PADD program.

In 2014, the Delaware P&A served 177 individual clients, held 29 trainings with 2,577 people trained, and provided informational and referral services to an additional 63 people. In addition to these activities, 15,280 people were impacted by the activities undertaken by the Delaware P&A on behalf of groups of clients. These activities benefited individuals statewide.

As an illustration of the work done by the Delaware P&A concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

#### Employment

The ADA bans discrimination based on disability for employers with fifteen (15) or more employees. Delaware employment discrimination law was consistent - banning discrimination based on disability for employers with fifteen (15) or more employees. However, Delaware employment discrimination law based on all other protected classes (e.g. age; sex) covered employers with four (4) or more employees. The Delaware P&A drafted legislation (S.B. No. 185) to achieve consistency, i.e., employers with four (4) or more employees would be prohibited from discriminating based on disability. Based on Department of Labor statistics, the result would be coverage of an additional 25% of employers (6,409) and 11.2% of employees (46,918). The Delaware P&A partnered with the State Council for Persons with Disabilities, prepared analyses, and received endorsements from fifteen (15) organizations. Endorsing agencies included the Arc of Delaware, United Cerebral Palsy of Delaware, Easter Seals of Delaware, Epilepsy Foundation of Delaware and the Department of Health & Social Services. The legislation was enacted and signed by the Governor on July 31, 2014.

The Division of Medicaid & Medical Assistance (DMMA) proposed adoption of a "Pathways to Employment" Medicaid program offering nine (9) services (including case management, supported employment, and non-medical transportation) to individuals with certain disabilities under age 25. The Delaware P&A authored extensive commentary which was adopted by multiple councils and shared with the Division. The Division adopted a final regulation with four (4) amendments prompted by the Delaware P&A commentary, including an explicit authorization for individuals with brain injury to qualify for the program, authorization to exceed a 6-month cap on job placement support services, and expansion of the scope of relatives authorized to provide compensated personal care. [17 DE Reg. 688 (1/1/14) (proposed); 17 DE Reg. 930 (3/1/14) (second proposed); 17 DE Reg. 1070 (5/1/14) (final)]

The Division of Developmental Disabilities Services (DDDS) issued a proposed regulation covering revisions to its Medicaid HCBS Waiver. Waiver services include supported employment and prevocational services. The Delaware P&A issued a comprehensive critique with nineteen (19) recommendations. Multiple councils adopted the Delaware P&A critique which was shared with the Division. The Division adopted a final regulation with three (3) amendments prompted by the commentary. Due to the amendments, individuals with brain injury were added to the covered population and 50 slots per year over a 5-year period were added to the Waiver authorization. [17 DE Reg. 950 (4/1/14) (proposed); 17 DE Reg. 1179 (6/1/14) (final)]

### Housing

Legislation (S.B. No. 143) was introduced which would affect resident rights in the context of long-term care facility transfer, discharge, and readmission. The Delaware

P&A participated in a small legislative hearing with the prime sponsor and representatives from the Department of Health & Social Services, multiple councils, and the nursing home industry. The Delaware P&A assisted with preparation of an amendment which was added to the bill. The amendment expanded protection for residents who leave a long-term care facility (including group home; foster home, and assisted living settings) for specialized care and wish to return to the long-term care facility. The amendment requires the facility to permit return or offer the next available opening. For example, if a group home resident were transferred to a nursing home for short-term wound care or rehabilitation, the resident would have an enforceable right to return to the group home. The resident would not have to languish in a more restrictive setting. The amended legislation was enacted and signed by the Governor on April 4, 2014.

### Education

The Department of Education proposed regulations to implement a new law authorizing grants to charter schools in specified contexts, including serving “high-needs students”. The DOE proposed regulation defined “high-needs students” as exclusively limited to “low economic status”. The DOE issued an analysis which included legislative history manifesting an intent to define “high-need students” as including students with disabilities. Multiple councils adopted the analysis which was shared with the Department. The Department adopted a final regulation which amended the definition to include students with disabilities. [17 DE Reg. 588 (12/1/13) (proposed); 17 DE Reg. 913 (3/1/14) (final)]

Transportation

DelDOT published a proposed plan to overhaul Delaware's paratransit system as a cost-cutting initiative. DelDOT proposed: 1) restricting paratransit service to the ADA minimum 3/4 mile fixed route corridor; 2) restricting eligibility to riders with disabilities only (eliminating eligibility based on age); 3) increasing fares; and 4) establishing a priority system for trips. On October 2, 2013, the Delaware P&A submitted commentary on the proposed changes which was adopted by multiple councils. The Delaware P&A submitted a second set of critical comments on November 19, 2013. The P&A also testified in a Joint Finance Committee hearing on the DelDOT budget on March 19, 2014. Based on public opposition, DelDOT deferred implementation of most changes and modified others. It raised fares effective July 1, 2014 but at a lower amount than proposed. It did not change eligibility standards, restrict services to the minimum ADA corridor, or establish a priority system for trips pending further review. As of September 30, 2014, no changes apart from increased fares had been adopted. The impact of deferring most changes had a widespread effect.

Thank you for this opportunity to submit this testimony.

**Written Testimony of Muna I. Naash, PhD of Oklahoma  
Labor, Health and Human Services, Education, and Related Agencies  
Subcommittee of the House Committee on Appropriations  
April 28, 2015**

**Usher syndrome researcher, George Lynn Cross and Edith Kinney Gaylord Presidential  
Professor, University of Oklahoma Health Sciences Center**

My name is Muna Naash and I am a biomedical research scientist. I have spent my career studying diseases of retinal degeneration and designing nanoparticle-based gene therapies to potentially treat the debilitating effects of vision loss. I have expanded my research interests and have been involved in Usher syndrome research for several years. As a vision scientist, I write on behalf of the Usher syndrome scientists striving to help Usher patients and respectfully request this committee prioritize funding for basic research in order to understand mechanisms of this disease and funding for translational research in order to identify therapeutic targets to treat this debilitating disease. As you prepare the Fiscal Year 2016 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language:

*The Committee commends NIH for including Usher syndrome on the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) list in order to track the annual support level of this rare disease. The Committee urges NIH to prioritize Usher syndrome research at the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI) and develop a multidisciplinary research strategy among multiple NIH institutes, including the National Center for Advancing Translational Sciences (NCATS), the National Human Genome Research Institute (NHGRI), and the National Institute of Mental Health (NIMH). Because Usher syndrome is a rare genetic condition, the Committee urges NCATS to support fundamental basic science research on Usher syndrome and NHGRI to support research on the underlying genetic causes of Usher syndrome. Since children and adults*

*with Usher syndrome are at risk for the development of mental and behavioral disorders, the Committee urges NIMH to support research to elucidate genomic risk factors that underlie mental disorders. The Committee urges additional focus from NIDCD, given Usher syndrome's involvement with vestibular dysfunction. The Committee requests an update in the fiscal year 2017 CJ on the planned and on-going activities related to this syndrome, including the manner in which various ICs coordinate on common goals and objectives.*

Usher syndrome is the most common cause of combined deafness and blindness. In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. I have made it a personal goal of mine to help these people. Last year, I had the opportunity to attend the Usher Syndrome Coalition's International Symposium on Usher Syndrome at Harvard Medical School. It was a very humbling and motivating experience. This conference had scientists, doctors, and patients all in attendance. Having the opportunity to meet and talk with the people living with this disease was inspirational.

Usher syndrome patients living with this disease show tenacity, strength, and endurance; striving as they walk through life with audiovisual impairment. I have dedicated my time and resources to studying the mechanism of hearing and vision loss associated with this disease. I currently study Usher syndrome type 2A and hope to, in time, study additional genetic subclasses of Usher syndrome. Entering this new field of research, I have found the community of Usher scientists to be extraordinary. They are passionately dedicated to their research, all with the goal to help patients.

As a private investigator studying Usher syndrome, more specifically USH2A, I have developed a unique mouse model to study one of the most common mutations detected in



patients with type 2A. This model is genetically modified to have the c.2299delG deletion mutation in the usherin gene. We chose this mutation to initiate our research because it affects the largest group of Usher syndrome patients. With that being said, every clinical type and genetic subtype of Usher syndrome needs to be studied. With added funding opportunities, we hope to generate more models for the exact defects seen in genes associated with this devastating syndrome to benefit Usher patients.

Using the model I have developed, I hope to elucidate the mechanism of Usher syndrome type 2A and generate gene therapies to treat this disease, first in this unique mouse model, then translating the results to humans. This technology can then be applied to the other Usher syndrome mouse models. I feel that if we as Usher syndrome scientists can identify a suitable target for treatment of one genetic subtype, the treatment for the other genetic subtypes will quickly follow.

I don't know what it is like to live without sight or hearing, but I can imagine that losing the two most important senses for communicating with the outside world leaves people feeling alone and hopeless. My goals are to help these patients, to give them sight and the opportunity to see the world as you and I can. Usher syndrome patients should be able to enjoy the things in life we all take for granted; hearing a song that moves them, watching the sun set, picking out their favorite color to paint their house. The bigger events in life that we look forward to are often not fully experienced by Usher syndrome patients, such as hearing their new baby cry or seeing their spouse's face when they say 'I do'.

People with Usher syndrome share the same range of intelligence and work ethic as any other slice of America. Yet they suffer from an 82% unemployment rate. People with Usher syndrome are born with the same emotional strength as any other American. Yet they have a

suicide rate that is 2 ½ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated \$139 billion annually in direct and indirect costs for people with eye disorders and vision loss. That doesn't even include the costs associated with hearing impairment.

I have spoken with and have met hundreds of people who are determined, focused, and working everyday to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells, which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Without Federal support, we cannot help any of the tens of thousands who have Usher syndrome, or countless others that will be born with this devastating genetic disorder in the future. There are dozens of different mutations that cause Usher syndrome, and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We are asking you to supply this last critical resource to help us find a cure.

Until very recently, there was no way of knowing how much money the National Institutes of Health (NIH) invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. Usher syndrome research still needs a lot more investment, but this is a great start.

We know funds are limited, however we request the committee ensure appropriate funding for Usher syndrome research. We are requesting that Usher syndrome research be made a priority and all possible available funds be dispersed amongst bench science, translational science, and clinical science to be most beneficial to patients with this disease. All we need is a chance to discover, a chance to help children and adults suffering from Usher syndrome, a chance to give them sight. With your help, we can have that chance.

**Testimony of Mr. James Lacy, Chairman  
Rotary International's Polio Eradication Advocacy Task Force for the United States**

Chairman Colc, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative (GPEI) is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to end polio forever. Rotary International supports the President's 2016 request of \$168.8 million for the polio eradication activities of the CDC to fully implement the polio eradication strategies outlined in the *Polio Eradication and Endgame Strategic Plan (2013-2018)*.

Thanks to this committee's funding for the 2014 polio eradication activities of the CDC:

- Eradication efforts have led to more than a 99% decrease in cases since the launch of the GPEI in 1988 and saved more than 13 million people from paralysis.
- Only 3 countries (Nigeria, Pakistan and Afghanistan) are polio-endemic – the lowest number in history. India and the entire Southeast Asia region were certified free from polio in 2014.
- Using lessons and infrastructure from polio eradication, Nigeria stopped an Ebola outbreak in 2014. Nigeria confirmed only six cases of polio in 2014 and no new cases since July 2014.
- There have been no cases of endemic polio on the African continent since August of 2014.
- The polio outbreaks from 2013-14 in the Middle East, Horn of Africa, and Central Africa have been brought under control.
- Type 3 polio may have been eradicated. There have been no cases of type 3 since Nov. 2012.

- Pakistan is now considered to be the only country in the world with uncontrolled transmission of wild polio and as of 2 April, accounts for 20 of the 21 polio cases that have been confirmed in 2015 (the other case is in neighboring Afghanistan).
- Lack of access to children in insecure areas continues to hamper progress. In Pakistan alone, more than 60 health workers and security personnel assigned to protect them have been killed in targeted attacks since November of 2012.
- Funding remains essential to addressing challenges in the remaining polio affected countries and protecting the gains made in at risk countries.

The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Rotary International appreciates the United States' generous support and recognizes increased funding provided by Congress in FY2015 to ensure the GPEI can fully implement the plan. Rotarians are committed to continuing their own fundraising for the program until the world is certified polio free. Rotarians will also continue to advocate support from the public and other governments, both polio free and polio affected, to support the successful execution of the *Strategic Plan*. The ongoing support of donor countries, like the United States, is essential to ensure the necessary human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free by the end of 2018.

Global polio eradication is Rotary International's top priority. Rotary's global membership of over 1.2 million business and professional leaders (more than 345,000 of which are in the U.S.) has contributed more than US\$1.3 billion toward a polio free world. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF.

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's increased support of CDC's polio eradication activities to support full implementation of the *Strategic Plan*. The United States is the leader among donor nations in the drive to eradicate this crippling disease. CDC has used the increased Congressional support provided in FY2015 to:

- **Globally:** In its role as a technical lead in the GPEI, CDC supports hundreds of field staff to complete polio eradication, including, notably, almost 200 STOP Polio assignees and large "National STOP" programs in Nigeria and Pakistan. CDC also supports other contractors to work in Africa and Asia and has detailed staff in several priority countries to work under WHO and from within CDC field offices. This large network is coordinated from CDC's headquarters in Atlanta.
- **Build capacity in Nigeria.** The National Stop Transmission of Polio (N-STOP) program, adapted from the original STOP Program, has provided Nigeria with an accessible, flexible, and culturally competent workforce at the front lines of public health. N-STOP includes participatory training for public health workers composed of ten modules covering poliomyelitis, vaccine management and monitoring, program management, and problem-solving practices. The Government of Nigeria and CDC partnered in the program's implementation, which has resulted in the placement of public health staff within the government structure in more than 170 communities throughout the north to strengthen local immunization teams. It has also supported training of 10,000 health workers across the 13 states to strengthen immunization systems and improve the quality of polio immunization. To date, N-STOP has engaged more than 60,000 nomadic settlements to expand vaccine provision to more than one million hard-to-reach children.

- **Build capacity in Pakistan.** Increased investment in Pakistan will focus on training and placing local personnel to strengthen the program in areas where access is possible. FY2015 has brought the focus to Pakistan, where the successful model of Nigeria is being adapted. Emergency Operations Centers have been established at the national and provincial level; and the National STOP program, adapted to Pakistan, is being implemented. CDC's efforts will also focus on an increase in cross border collaborations between Afghanistan and Pakistan to intensify Polio eradication activities.
- **Laboratory Surveillance:** Investment with CDC's Polio Global Reference Lab will allow the recruitment of additional staff, training for country and regional labs, essential IPV research, and expansion of environmental surveillance capabilities in the field. CDC provides technical and programmatic assistance to the global polio laboratory network through the Polio Laboratory in CDC's Division of Viral Diseases. CDC's labs provide critical diagnostic services and genomic sequencing of polioviruses to help guide disease control efforts. CDC will continue to serve as the global reference laboratory, while expanding environmental surveillance in countries to serve as a "safety measure" to detect any polioviruses circulating in areas without cases. Kit distribution and proficiency testing for ITD and sequencing.
- The polio infrastructure, built with significant CDC input and support, adapted quickly to respond to an importation of Ebola in October 2014 in Lagos by establishing an Emergency Operations Center in Lagos and stop the outbreak. Polio immunization rounds in northern Nigeria continued as planned without a decrease in quality demonstrating the program in Nigeria, and the adaptability of polio assets for use in other public health issues.
- CDC funds are also used to purchase oral polio vaccine to immunize children against polio.

- Through its cooperative agreement with WHO, CDC provides funding for immunization activities in high risk and polio infected countries. CDC collaborates closely with UNICEF and provides critical support on analysis and use of campaign results to identify and address reasons why children are missed and address vaccine hesitancy concerns.
- CDC's investment in immunizations systems strengthening supports the introduction of Inactivated (Salk) Polio Vaccine (IPV) to focus countries, other GAVI-eligible countries, and to non-eligible countries.

For Fiscal Year 2016, we request this subcommittee to provide \$168.8 million for the CDC's polio eradication activities, the level that was requested in the President's budget. This will allow CDC to provide to continue to build capacity to support intense supplementary immunization activities in polio-affected and at-risk countries, to develop leadership on data management and evidence-based decision making, and to implement for effective management and accountability. These funds will also help maintain essential certification standard surveillance. Finally, continued funding will enable CDC to capitalize on polio eradication efforts to strengthen immunization systems and protect the gains made in polio free and at-risk countries.

Since 1988, tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other infectious diseases and will do so beyond polio eradication.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the GPEI could provide net benefits of at least \$40-50 billion over the next 20 years. As many as 200,000 children could be paralyzed annually in the next 10 years if we do eradicate polio now.



From: Jean Fox Csaposs, former Board chair of Heightened Independence & Progress (*hip*), Centers for Independent Living for People with Disabilities in Bergen County and Hudson County, New Jersey.

I am writing today to support the urgent request of the National Council on Independent Living to increase the HHS budget for Independent Living by an additional \$200 million, for a total of \$306 million.

I have been a volunteer with Heightened Independence & Progress (*hip*) for 27 years, serving in several capacities on our Board of Trustees, including two extended terms as Board chair. My close involvement with *hip's* mission and work has made me fully aware of how essential our federal funding has been in helping literally thousands of our "consumers" to live their lives as independently as possible. Helping people with disabilities to stay in their homes and be part of their communities, rather than be relegated to institutions, is a fundamental principle behind our work. Our small but dedicated staff make every dollar work for the benefit of the many people in need in both counties we serve.

Centers for Independent Living have already seen their federal funding cut. I urge those making these vital decisions not only NOT to cut further in the future, but instead to increase the HHS budget for Independent Living by an additional \$200 million of urgently needed funds.

*Written Testimony for the Record to the House Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies regarding FY 2016  
Appropriations for HIV/AIDS Programs  
Submitted by Dr. Adaora Adimora, MD, MPH, FIDSA, on behalf of the HIV Medicine  
Association (HIVMA)  
April 28, 2015*

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. As you work on the FY2016 appropriations process, we urge you **to invest in the medical research supported by the National Institutes of Health (NIH)** and sustain robust funding for **the Ryan White Program at the Health Resources and Services and Administration (HRSA)** as well as the **Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs.**

Early access to effective HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.<sup>1</sup> Treatment not only saves the lives of individuals with HIV but directly benefits public health by reducing HIV transmission risk to near zero.<sup>2</sup> However, despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious epidemic in the United States with a record 1.1 million people living with HIV and an estimated 50,000 new infections occurring annually. In our country, HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. The rate of new HIV infection in African Americans is 8 times that of whites based on population size.<sup>3</sup> Globally there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan

Africa. We are beginning to see improvements thanks in large part to U.S. investments in programs like PEPFAR, and the CDC Global AIDS Program is a critical partner in country level efforts to achieve epidemic control. We call for a funding level of at least \$132 million to sustain CDC this this vital lifesaving role.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to mount an effective response to the domestic HIV epidemic and meet the need in communities across the country.

**NIH – Office of AIDS Research (OAR): HIVMA strongly supports an FY 2016 funding level of at least \$32 billion for the NIH, including at least \$3.2 billion for the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of men, women and children in the U.S. and in the developing world. Years of flat funding for biomedical research has eroded our capacity to sustain our nation’s historic worldwide leadership in HIV/AIDS research and innovation, and is discouraging cultivation of the next generation of scientists.**

Our past investment in comprehensive HIV/AIDS research paid off enormously in dramatic gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. This research also helped reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available.

Strong, sustained NIH funding is a critical national priority that will foster better health, economic revitalization and game-changing new discoveries that hold promise for an HIV

vaccine and ultimately a cure. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. Congress should ensure our nation does not delay vital HIV/AIDS research progress.

**HRSA – HIV/AIDS Bureau (HAB): It is critical to maintain level funding for the Ryan White Program, which annually serves more than half a million individuals living with HIV. The Ryan White Program provides expert, comprehensive HIV care and treatment that helps most patients achieve viral suppression, allowing them to live for close to a normal lifespan and reducing their infectiousness to others to almost zero. Estimated authorization levels for the program in FY 16 would call for an increase of at least \$136 million to the Ryan White program. For Ryan White Part C program, that supports HIV medical clinics, HIVMA requests \$225.1 million, or a \$24 million increase. These additional funds would help to support the ever increasing need for these lifesaving services. Part C HIV medical clinics currently struggle to meet the demand of increasing patient caseloads. The expert, comprehensive HIV care model or “medical home” that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. Patients with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed.<sup>4</sup> *We also know that the annual health care costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.*<sup>5</sup>**

Additionally, while HIVMA welcomes the proposed increase for Part C programs in the President's FY 2016 budget, we do not support the proposal to consolidate Ryan White Part D funding into Part C. Ryan White Part C and D programs both provide comprehensive, effective

care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women, including pregnant women, HIV-exposed infants, and young people in care. The programs provide services tailored to women and young people and in some communities, Part D-funded programs are the main providers of HIV care and treatment.

While the Affordable Care Act (ACA) provides important new health care coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion, especially in the South, necessitate an essential and ongoing role for the Ryan White Program to avoid life-threatening and costly disruptions in care.

**CDC - National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention**

**(NCHHSTP):** HIVMA strongly supports the much needed increase of \$44 million proposed in the President's FY 2016 budget for the CDC's NCHHSTP, especially the proposed **\$31.5 million for viral hepatitis, as well as increases of \$6.3 million for HIV prevention and surveillance, and \$6.3 million for the Division of Adolescent School Health (DASH).** We are also especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least \$3.3 million to that line item for a total of \$132 million, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.

**Policy Riders – Remove the Harmful Ban on Federal Funding for Syringe Exchange**

**Programs:** HIVMA strongly urges the Committee to lift the ban on federal funding for syringe exchange programs (SEPs). HIVMA is committed to evidence-based public health interventions

that both increase access to health care and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major route of transmission for these infectious agents. Because transmission occurs through the sharing or re-use of infected paraphernalia, access to uninfected injection equipment is a key part of infection prevention programs – and is especially critical at this time, given the recent resurgence of injection drug use in many parts of the nation. The current HIV outbreak in Indiana, which is related to injection drug use, underscores the salience of this issue.

SEPs also help improve individual and community public health by engaging individuals in medical care. SEPs are associated with decreases in HIV and viral hepatitis incidence, and provide an important point of healthcare access, including initiation of HIV and viral hepatitis education, counseling and testing, and entry into substance use treatment. SEPs also benefit community safety by reducing the number of improperly disposed syringes as well as reducing needle stick injuries to law enforcement officers and other first responders.

**Conclusion: We are at serious risk of losing ground against the HIV pandemic if we fail to prioritize public health and research programs. HIV remains the leading infectious killer worldwide, and we must fully leverage and invest in HIV prevention, care and treatment and research to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe.**

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<sup>1</sup> Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. *New Engl J Med* 2009;360:1815-26.

<sup>2</sup> Cohen, Myron S., et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. 2011 *New England Journal of Medicine* 493-505: V365, no 6, <http://www.nejm.org/doi/full/10.1056/NEJMoa11052>

<sup>3</sup> CDC Fact Sheet, February, 2014, accessed online at: <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>

<sup>4</sup> Bradley, H., et al. Ryan White HIV/AIDS Program Assistance and HIV Treatment Outcomes in the United States. CROI 2015. Abstract: 1064. Accessed online at: <http://www.croiconference.org/sessions/ryan-white-hiv-aids-program-assistance-and-hiv-treatment-outcomes-united-states>.

<sup>5</sup> Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. *AIDS Care*.2008;20:1050–6.

Statement for the Hearing Record  
Before United States House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Thursday, April 23, 2015

Hearing on  
Programs Serving Native Americans

Statement of  
National Organization on Fetal Alcohol Syndrome

Chairman Cole, Ranking Member DeLauro, members of the Subcommittee, on behalf of the National Organization on Fetal Alcohol Syndrome (NOFAS) and our 41 affiliated organizations, we thank you for the opportunity to submit this statement for inclusion in the record.

We commend the Committee for addressing the health needs of American Indians and Alaska Natives (AI/ANs) and the 566 federally recognized Tribes. NOFAS expresses its avid support for the requests offered in hearing testimony, including the consideration of Tribal set-asides at HHS, Committee direction to develop legislative language to expand self-governance within HHS beyond IHS, enhanced support for CDC Tribal Epidemiology Centers and the assurance that the agency's capacity building support reaches AI/AN-specific organizations, and increased funding for SAMHSA Tribal Behavioral Health Grants (Native Connections) and Circles of Care program.

One of the most significant public health problems for Native American is alcoholism and its consequences. AI/AN populations are five times more likely than whites to die of alcohol-related causes, including liver disease, and experience higher rates of drunk driving and alcohol-related deaths than the general population.<sup>1</sup> Excessive alcohol consumption is the leading cause of preventable death among AI/ANs, according to a report issued by CDC and IHS, accounting for 11.7 percent of all deaths among AI/ANs – nearly twice that of the general population.<sup>2</sup>

One tragic consequence of alcohol use, often overlooked, is Fetal Alcohol Syndrome (FAS), now more commonly identified as Fetal Alcohol Spectrum Disorders (FASD).<sup>3</sup> FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

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<sup>1</sup> Substance Abuse and Mental Health Services Administration, 2012

<sup>2</sup> Indian Health Service and Centers for Disease Control and Prevention, 2014

<sup>3</sup> From 1973, when the disorder was discovered in U.S. medical literature, the primary term used to describe alcohol-related birth defects was Fetal Alcohol Syndrome. In 2004, the term Fetal Alcohol Spectrum Disorders was defined and adopted as a better description of the range of diagnoses associated with prenatal alcohol exposure. Fetal Alcohol Syndrome remains in use as a diagnosis under the FASD umbrella. (NOFAS FASD Terminology Summit, 2004)

While FASD is a health concern among all populations that consume alcohol, from 1981 to 1991 the recorded prevalence of FAS among AI/ANs stood at 31 per 10,000 births compared to 2.1 in the overall U.S. population.<sup>4</sup> A 2007 study reported the prevalence of FAS in Alaska to be 1.5 per 1,000 live births, but 5.6 among ANs. The most recent findings, published in the November 2014 edition of *Pediatrics*, measure the rate of FASD among school-aged children in the United States at one in 50, if not higher.<sup>5</sup>

NOFAS urges the Committee to continue to meet the need for AI/AN-specific funding across HHS as called for in hearing testimony. Additionally, NOFAS asks the Committee to support existing FASD/FAS funding at CDC, SAMHSA, NIAAA, and HRSA, while ensuring that these agencies appropriately address this pressing health concern among AI/ANs, and to favorably consider the programmatic request that will in part support a Native American-focused FASD collaborative. This request modestly offsets the dramatic \$8.8 million reduction in FY 2014 FASD funding within HHS, as the long-standing \$9.8 million line item for FASD at SAMHSA was reduced to \$1 million enacted for FY 2015 and requested for FY 2016.

Thank you for the opportunity to present our perspective.

#### **About the National Organization on Fetal Alcohol Syndrome**

NOFAS is a public health advocacy, nonprofit organization supporting individuals, families, and communities living with Fetal Alcohol Spectrum Disorders (FASD) and striving to prevent alcohol exposed pregnancies. FASD is completely preventable when pregnant women abstain from alcohol, and it is at least as prevalent as Autism. Recognizing 25 years of excellence, NOFAS works closely with American Indian and Alaska Native communities and organizations to address alcohol-related birth defects.

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<sup>4</sup> (J. Hisnanick, 1992; P. A. May, 1996; J. M. Wallace et al., 2003)

<sup>5</sup> P.A. May et al. *Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders*. *Pediatrics* 2014; 134:5 855-866



**Testimony of William J Whited**  
**Oklahoma State Long-Term Care Ombudsman**  
**Member, National Association of State Long-Term Care Ombudsman Programs**  
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*Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – Addressing the Administration for Community Living (ACL)*

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I am pleased to present this testimony on behalf of residents and tenants residing in Oklahoma long-term care facilities in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of the Long-Term Care Ombudsman Program (LTCOP) and all the vulnerable citizens that it serves. This statement and the following funding recommendations are submitted for the Fiscal Year 2016 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL).

First, we request \$5 million to **support the work of the LTCOP under the Elder Justice Act**. This appropriation would allow states to hire additional staff and leverage that staff to recruit additional volunteers to help support the investigation of complaints of abuse, neglect, and exploitation of residents of nursing home and assisted living facilities. To date, no EJC funds have been provided for the LTCOP.

Second, we request \$20 million to **support 333 additional Ombudsman** (salaried staff) at an estimated \$60,000 average annual salary/fringe benefits and necessary staff training. The requests adds new ombudsman positions specifically dedicated to providing Ombudsman services to residents of assisted living facilities and other community-based long-term care delivery systems, which currently suffer from a significant lack of personnel resources around the country.

Third, we request \$16.83 million authorized under Title VII of the Older Americans Act for LTCOPs to **restore funding back to the FY 2011 level**. Programs in every district and state are suffering from recent cuts. These funds would help in a partial way to restore our reduced ability to visit residents in nursing homes.

The primary function of the LTCOP in the federal OAA is to identify, investigate, and resolve complaints that relate to action, inaction or decisions that may adversely affect the health, safety, welfare, and rights of residents of long-term care facilities. Ombudsman representatives work with the consent and at the direction of residents in the resolution of their problems. They visit residents living in nursing homes and residential care homes. Ombudsman representatives ask them about problems or concerns they have and if they need or want our help to resolve these issues. Ombudsman representatives act as their advocates. We strongly believe that our work not only improves the quality of life for millions of long-term care facility residents, but also

saves Medicare and Medicaid resources by avoiding unnecessary costs associated with poor quality care.

Nationally, in Fiscal Year 2013, nearly 12,000 volunteers, including 8,290 individuals certified to investigate complaints, and 1,233 staff (full-time equivalent) served in the LTCOP. Ombudsmen investigated and worked to resolve 190,592 complaints made by 123,666 individuals. Ombudsmen were able to resolve or partially resolve 73%, or almost three out of every four complaints investigated. In addition, ombudsmen provided information or consultation on rights, care and related services approximately 500,000 times.

Oklahoma's LTCOP is responsible for advocating for 27,846 residents and tenants residing within 621 long-term care facilities. The Oklahoma Office of State Long-Term Care Ombudsman consists of the State Long-Term Care Ombudsman, Deputy State Long-Term Care Ombudsman, an Administrative Programs Officer, One Administrative Assistant, two Program Field Representatives, twenty-three fulltime Ombudsman Supervisors, one halftime Ombudsman Supervisor and numerous volunteers.

In federal Fiscal Year 2014, Oklahoma's LTCOP received 5,646 complaints by or on behalf residents; and provided 7,941 consultations, education sessions, visits, and other activities. Our office advocates for 27,846 residents in 621 facilities and we do this with limited staff and declining volunteer numbers. We are grateful for the funding that we do have, but feel that the federal funding for the operation of the Oklahoma LTCOP should be increased. Currently federal funding comprises less than half of the funding required to maintain the Oklahoma program at its current level. The additional funding would not only support elder justice activities it would support avenues to recruit more volunteers and ultimately improve the quality of care and quality of life of Oklahoma's long-term care facility residents.

We understand that this Subcommittee faces a strained financial situation, but a continued commitment to Ombudsman programs advocating for the health care needs and safety of millions of older adults living in nursing homes and assisted living facilities across the nation should remain a high priority. Since 1978, the LTCOP has been a core program of the OAA. It is the only program in the OAA that specifically serves residents of nursing homes and assisted living facilities. We all appreciate and value the importance of living in one's own home. The OAA provides critically needed home and community based services that often delay institutionalization. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. These residents are usually frail and extremely vulnerable and rely on the advocacy services of the LTCOP.

Demand for our services and advocacy is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers. These violations put facility residents in immediate jeopardy of harm. This trend suggests a frightening decline in the quality of long-term care services. Ombudsmen are needed now more than ever in nursing homes, board and care facilities, and in assisted living communities. As well, the demand placed on the program

**Testimony of William J Whited**  
**Oklahoma State Long-Term Care Ombudsman**  
**April 29, 2015**

by the need to assist residents who are relocating from long-term care facilities that are downsizing or closing their doors continues to complicate ombudsman programs' daily operations.

Administrators in many long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation and this form of outreach has also placed an increasing strain on available advocacy resources. In order to improve advocacy and services available to residents of long-term care facilities, the Oklahoma Office of the State Long-Term Care Ombudsman and NASOP supports the aforementioned funding levels.

Overall, Ombudsmen offer valuable consumer protections to residents and provide a voice for those unable to speak for themselves. Every day in America, 10,000 more persons reach the age of 65 years. With a rapidly growing older population, LTCOPs can continue to enhance the quality of life, improve the level of care, protect the individual's rights and promote the dignity of Americans across the nation. NASOP, formed in 1985 as a non-profit organization, is composed of state long-term care ombudsmen representing their state programs created by the Older Americans Act (OAA).

Thank you for your ongoing support.

**STATEMENT OF THE NATIONAL KIDNEY FOUNDATION  
30 EAST 33<sup>RD</sup> STREET NEW YORK, NY 10016**

**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES**

**FISCAL YEAR 2016 HHS APPROPRIATIONS**

**Submitted by Troy Zimmerman, Vice President for Government Relations**

**April 29, 2015**

The National Kidney Foundation (NKF) is pleased to submit testimony in support of the Centers for Disease Control and Prevention Chronic Kidney Disease Program, the National Institute of Diabetes and Digestive and Kidney Disease, and the Health Resources and Services Administration Division of Transplantation. We respectfully request FY 2016 funding of \$2.2 million for the CDC Chronic Kidney Disease Program, \$2.066 billion for NIDDK, and \$26.5 million for the HRSA Division of Transplantation.

Over 26 million people have CKD, yet only 10% are aware they have it.<sup>1</sup> A recent study shows the burden of kidney disease is increasing and that over half of U.S. adults age 30-64 are likely to develop CKD.<sup>2</sup> Early intervention can improve outcomes, lower costs, and improve patient experience, yet in a recent study only 12% of primary care clinicians were properly diagnosing CKD in their patients with diabetes, who are at the highest risk of kidney disease.<sup>3</sup>

While progression of CKD can lead to End Stage Renal Disease (ESRD), CKD patients are at a greater risk of death, cardiovascular events and adverse drug events. An American Heart

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<sup>1</sup> Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. Aug 2011;6(8):1838-1844.

<sup>2</sup> Hoeger, Thomas, et al. The Future Burden of CKD in the United States: A Simulation Model for the CDC CKD Initiative, Am J Kidney Dis. 2015;65(3):403-411.

<sup>3</sup> Szczech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type-2 Diabetes: The ADD-CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), PLOS One November 26, 2014.

Association task force noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function.<sup>4</sup> Testing for kidney disease in at risk populations provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors. This is why last year NKF announced an initiative to help improve early detection and diagnosis of CKD by primary care practitioners, but we cannot do this alone.

In 2012, more than 636,000 Americans had ESRD, including more than 450,000 dialysis patients and the remainder kidney transplant recipients, with minority populations disproportionately affected. While improved care management, blood pressure control, dietary intervention and lifestyle improvements can delay progression of kidney disease for many individuals, further research into the causes of progression and the reasons why some individuals progress faster than others is needed. Expanded efforts at the CDC and NIDDK are needed to help us further our goals to improve outcomes for kidney patients and answer the many unknowns in kidney disease that ultimately may lead to improved treatments or even some day put a stop to kidney disease.

In 2012, ESRD was present in less than 2% of Medicare beneficiaries but responsible for nearly 6% of Medicare expenditures.<sup>5</sup> Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with diabetes, cardiovascular disease, or hypertension (two-thirds of ESRD patients have diabetes or hypertension). A kidney transplant, for most patients, has superior outcomes over dialysis and lower healthcare costs.

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<sup>4</sup> Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. *Circulation* 2003; 108: 2154-69.

<sup>5</sup> 2014 U.S. Renal Data System Annual Report.

However, nearly 102,000 individuals are awaiting a kidney transplant and about 16,000 individuals receive a transplant each year. Improving access to kidney transplantation is vital to improving the lives of those with kidney failure and lowering health care costs. Additional funding for HRSA DoT can help address this gap.

### **CDC Chronic Kidney Disease Program**

In 2006, NKF worked with Congress to initiate a Chronic Kidney Disease Program at CDC with a focus on early detection and treatment. NKF urges the Committee to provide \$2.2 million for the CKD program for FY 2016, an increase of \$100,000. NKF's CKD Primary Care Initiative aims to transform detection and care of CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools. Our initiative will build on CDC's program efforts.

The CDC program delivers vital research and projects to identify and control CKD risk factors, raise awareness, and promote early diagnosis and improved outcomes for those with CKD. These include (1) demonstrating approaches for identifying individuals at high risk through state-based screening; (2) conducting an analysis on the economic burden of CKD and the cost-effectiveness of interventions; and (3) establishing a CKD surveillance system by analyzing and interpreting information to assist in prevention and health promotion efforts for kidney disease. The surveillance project includes a CDC website program with information on risk factors, early diagnosis, and strategies to improve outcomes.

The CDC CKD program addresses three priorities in the *National Strategy for Quality Improvement in Health Care*, including 1) making care safer by reducing harm caused in the delivery of care, 2) promoting the most effective prevention and treatment of the leading causes of mortality, starting with cardiovascular disease, and 3) working with communities to promote

widespread use of best practices to enable healthy living. The program is also vital to accomplishing CKD related goals in *Healthy People 2020*.

Congressional support for an increase in funding to the CDC program will benefit kidney patients and those at risk for kidney disease, advance the objectives of Healthy People 2020 and the *National Strategy for Quality Improvement in Health Care*. CDC's priorities going forward include addressing disparities among racial and socioeconomic populations and adding local data on CKD including additional risk factors. This momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not increased.

### **NIDDK**

NKF joins other members of the Friends of NIDDK to request \$2.066 billion for the Institute in FY 2016. Medicare spends \$87 billion annually to care for patients with kidney disease, including nearly \$29 billion for individuals with ESRD, yet NIH funding for kidney disease research is only about \$600 million annually.

In March, NKF hosted the Second Annual Kidney Patient Summit with participation by nearly 100 advocates from NKF and five other kidney patient organizations. Increased federal support for kidney research was a top priority in the advocates' congressional meetings and is particularly important for individuals with genetic kidney disease. NIDDK Director Dr. Griffin Rodgers addressed the advocates and discussed exciting opportunities in CKD research. Scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD. With the unique status of ESRD in the Medicare program, CKD research has the potential to provide cost savings to the federal government like that of no other chronic disease.

Many individuals at high risk of CKD rely on community health centers for their health care services. NKF believes this represents a valuable opportunity to provide information to

patients on risk factors and increase detection of CKD in early stages. We urge Congress to direct NIDDK to build upon its efforts from 2008-2010 to “test effective strategies for improving CKD detection and care in primary care settings, focusing primarily on integrating CKD into diabetes care” in community health centers as a method to better reach Americans who are most vulnerable to kidney disease.<sup>6</sup>

### **HRSA Organ Transplantation**

NKF urges the Committee to provide \$26.5 million for organ donation and transplantation programs in the HRSA Division of Transplantation, \$3,000,000 above the President’s Request.

Kidney recipients often have an improved quality of life and are more likely to participate in the work force. Transplantation is tremendously cost effective -- Medicare spends about \$25,000 per year on a kidney recipient after the year of transplant, compared to more than \$86,000 annually on a dialysis patient. The National Donor Assistance Program has helped more than 4,800 individuals obtain a transplant by assisting living donors with expenses such as travel and subsistence that are not reimbursed by insurance, a health benefit program, or state or federal programs. A recently established NKF task force to identify opportunities to expand the number of transplants continues to develop its recommendations, with financial constraints frequently cited as a barrier to living donation. Additional funding for the Donor Assistance Program will enable more individuals to consider being a living donor.

Thank you for your consideration of our FY 2016 funding requests.

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<sup>6</sup> Quality Improvement in Primary Care Settings, National Kidney Disease Education Program, National Institutes of Health, NIDDK, October 10, 2012 <http://nkdep.nih.gov/identify-manage/quality-improvement.shtml>.



**Statement of Michael Riksen**  
**Vice President – Policy & Representation, National Public Radio**  
**Before the Subcommittee on Labor, Health and Human Services, Education and Related**  
**Agencies, U.S. House Committee on Appropriations**

April 29, 2015

Dear Chairman Cole, Ranking Member DeLauro and Members of the Subcommittee,

Thank you for this opportunity to urge the Subcommittee's support for an annual federal investment of \$445 million to public broadcasting through the Corporation for Public Broadcasting, (CPB) for Fiscal Year (FY) 2018. Public radio joins with our public television partners in urging the Subcommittee's support for \$40 million in FY 2016 for the first year of a \$197 million multi-year request to replace the current public television interconnection system, and \$25.74 million for the Department of Education's Ready To Learn program. With your support, and these essential funds, every American will continue to have free access to the best in educational, news, information and cultural programming.

I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, our more than 950 public radio station partners, other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many stations, both large and small, that create and distribute content through the Public Radio Satellite System (PRSS).

Funding provided by Congress to the CPB supports the entire foundation of a system that has been one of America's most successful models of a community-centric grant program. The cost of public broadcasting is only 0.01% of the entire federal budget. The revenue base provided by Congress enables stations to raise \$6 for every federal grant dollar. This federal financial investment permits local stations to invest more deeply in their own local news and cultural programming which in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and on online.

With support from CPB's community service grants, each of the hundreds of independently operated public radio stations is responsible for curating and creating the mix of programs that best addresses the needs of their local community. These stations and their programming choices are as diverse as the people who live in the communities they serve. Some have all-news formats. Others have all-music formats and still other blend news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the federal government invests roughly \$90 million dollars in the operation of America's local public radio stations. And these stations provide service to all of America's congressional districts and states.

In Oklahoma, for example Chairman Cole, local public radio stations know just how important federal funds are to the local services provided to your constituents. Public radio stations bring local, regional, national and international programming to thousands of listeners in Oklahoma. Stations in the Sooner State use CPB community service grants to support exemplary service to local residents and provide a variety of local programming such as *Oklahoma Voices*, *All This Jazz*, *Oklahoma Music Minute*, *Midday Concert*, *Assignment: Radio*, *Oklahoma Rock Show*, *Big Band Saturday Night*, *Slice of Life*, *Business Intelligence Report*, *Folk Salad*, *The Texoma Report*, *One Six 8*, *Business World*, *Weekend Blues*, and *The Wall Street to Main Street Report*.

Similar services are provided by public radio stations in Connecticut but, of course, locally produced programming will be different when compared to other regions of the country. Each of our independently owned and operated stations possesses their own "secret sauce" for developing and airing popular local programming. Public radio listeners living in the Constitution State will hear wonderfully produced local programming such as *Join the Conversation*, *Jazz Corridor*, *Spotlight on the Arts*, and *Where We Live*, a talk show about living in Connecticut, in New England, in the United States, and on the planet (sometimes even beyond). On any given day, you can hear interviews with elected officials, musicians, authors and community leaders or roundtables on transportation and infrastructure, the latest scientific breakthroughs, changes in the health care system, education in the 21st century, and the effects of worldwide events on local communities. Stories are shared about neighbors doing amazing things to improve life in cities and towns.

Federal funding for public broadcasting is a small investment that pays big dividends. And when it comes to music, public radio plays a unique and critically important role. We have created a value partnership that connects music and those who devote their lives to it from artists, performers and composers to audiences. Our local stations play a significant role in music discovery, preservation, education, and local music economies. And this role is enabled by CPB's community service grants to local public radio stations.

Nationally, more than 260 public radio stations have full-time music formats and an additional 628 play music as part of their programming lineups. On the whole, local public radio stations air more than 5.5 million hours of music per year, the majority of which is local programming and host more than 10,000 in-studio and community-based performances.

Public radio provides a home for genres that are economically unsustainable in the commercial market, including classical, jazz, folk, opera and traditional regional music such as bluegrass and zydeco. In fact, over 90% of all broadcast classical music in America is available only on public radio, and the same is quickly becoming true for jazz. Our stations help support and preserve cultural institutions, including local bands, symphony orchestras, philharmonic societies, theater groups, and historical venues. Public radio's role in music is not possible without a diverse revenue base, including CPB's financial support to local stations.

Mr. Chairman and Ranking Member DeLauro, NPR and the public radio system are committed to being America's public radio where rationale, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take

sides. Public radio plays an important, significant and growing role in news, journalism, talk and music/cultural programming. Our stations are essential to, and part of, the communities they serve.

Through news, talk, music and cultural programming, public radio stations are reaching out to audiences wherever they are. We're embracing America's changing demographics and using digital media to connect better, more quickly and in more diverse ways. Today's public radio isn't going away, it's going everywhere and we are working every day to earn the trust of the 38 million Americans who rely on us for news and insights that guide and inform.

My thoughts about autism, sensory processing (or integration) disorder, and the need for subsidized housing that takes into account the special need of the ASD individual with life-limiting sensory processing issues.

Why communal atmosphere is bad for some on the autism spectrum (particularly those who face severe problems with sensory processing):

- Randomness; lack of routine and predictability as faced in most typical living environments.
- Chance for harm: victimization due to natural gullibility (lack of "street smarts").
- Lack of adequate transportation due to communal conflict with regular public transportation, family not always being able to travel to drive the individual where they need to go.
- Alienation and condemnation from others, even from those on the autism spectrum without severe sensory impairment (think a lot of those with Asperger's Syndrome, though in some cases even those with the "milder" form of autism do experience severe sensory processing disorder (though usually it is easier to handle as has been my experience in talking to those with AS online via You Tube).
- Little or no autonomy for the individual. Heavy rely on family and any community, financial supports.
- High stress level and underlying depression that paves the way for other health problems like heart disease, hypertension, depression and suicide (not to mention worsening of related diagnoses such as OCD).
- More reliance on Rx medication to combat anxiety and impulsivity issues arising from a random, "one size fits all" sensory environment.
- Being involved in a crime (due to lack of inhibition, esp. if under constant duress from an ongoing constant such as a neighbor's dog yapping or kids screaming on swing sets in summer.) Such as yelling at or hitting another person during a conflict.

What I envision:

An assisted-living model facility for those with ASD with the dynamic of SPD in medical need of a low-sensory environment.

- Subsidized (at least a majority of them) so that those who don't have rich parents can have a clean and safe place to live, covered by disability (SSDI) and any supplemental money they earn from employment (for those who can be employed). Section 8 or Section 42.

- A letter from the doctor explaining why the individual applying to live in such a place as described vs. a "one-size-fits-all" environment, group home or institution.
- Individual apartments for 1-2 people (no children).
- Transport service at little or no cost to residents.
- This would not be a place for extremely low functioning people on the spectrum nor those who are unaffected on the sensory level as to withstand the loud sounds of children. For those wanting families, opportunities exist elsewhere.
- Community room for residents to socialize (to learn *how* to socialize and be accepted) that is sensory friendly. Appropriate lighting, audio equipment in TV/Stereo speakers (light/sound filtering). No olfactory distractions like air-fresheners. No pets present, so no pet dander or noise issues. Simple exercise equipment (treadmill, exercise bike, hand-weights)
- Green space outside for residents to form a community project such as a fresh garden to eat healthy.
- Assistants- "go to" people for residents to reach out to without fear of retaliation or eviction when they get frustrated and need help dealing with adult life.
- Employment (for those who can work). Connect companies who want to grow jobs here in U.S. with a facility like I am proposing both in the community and via the internet for those who work best from their low-key, sensory friendly home.
- Keep this an oasis from the sensory storm called life while at the same time, promoting both autonomy and socialization to avoid isolation.

Generation Y stands poised like a tidal wave to flood the economy. Those with autism and accompanying disorders that make everyday life unlivable if not for special accommodations and supports will struggle long after the recession has ended. They won't be able to have a place to live let alone work or connect with others-something most take for granted. Taking the sensory-integration model into account, I can personally say that I could be an *asset* to my community if such a place as previously described existed. The economy would benefit from whatever education and job-placement I would receive via an occupational therapist. I would benefit from being able to meet and make friends in a low sensory environment. Finally, parents could meet their Maker knowing their adult children are safe. Both can enjoy the time they have left together.

I should also say that this environment would be inclusive to the community. Residents with visitors of all ages would be welcome (providing they did not create an unreasonable disturbance). Links with community non-profits to provide social gatherings, outings, creative outlets, spiritual purpose, etc.

Regards,

Allison M. Kramer

Testimony Submitted to the United States House Committee on Appropriations,  
Sub-Committee on Labor, Health and Human Services,  
Education, and Related Agencies Concerning the FY16 Budget

Fraser Nelson  
Director of Data and Innovation  
Salt Lake County Mayor's Office

Date: April 29, 2015

On behalf of Mayor Ben McAdams of Salt Lake County, Utah, I am pleased to submit this statement in strong support of the Social Innovation Fund administered by the Corporation for National and Community Service (CNCS) and its continued funding in the FY16 Budget. The Social Innovation Fund (SIF) connects public and private resources to find creative solutions to our hardest social problems, including criminal justice, substance abuse, maternal and child health, domestic and sexual violence, educational under-achievement, homelessness, and many others. SIF is reshaping the policy landscape by focusing governments on data and outcomes and helping support an ecosystem where great ideas can be tested and improved. It is upending the notion of continuing to support programs we think will work, or that we hope will work, with those that result in demonstrably better lives for those who participate in the programs. During Mayor McAdams' tenure at Salt Lake County—a metropolitan area serving nearly 1.1 million residents and growing—SIF funding has helped make data and evidence-based practices part of our government DNA.

An important benefit of the Fund is its role in Pay for Success, an innovative funding model that ensures taxpayer dollars only flow to what works, and the human costs of participating in programs that don't work are greatly diminished for the citizens we serve. The Social Innovation Fund has been a catalyst in the process of scaling the

Pay for Success model across the western United States. Pay for Success leverages private and philanthropic resources to fund social interventions upfront in exchange for a modest return *if* the program achieves specific outcomes. The funding model gives government an opportunity to improve services without straining budgets or putting taxpayer money at risk.

In June 2013 Mayor McAdams, in partnership with the United Way of Salt Lake, Goldman Sachs, and J.B. Pritzker, launched the first-ever county Pay for Success effort to finance high quality preschool education. This initiative, which received bipartisan support from the Salt Lake County Council, provided expanded access to high quality early childhood education for 600 low-income students in the Granite School District. The goal is to close the achievement gap between the economically disadvantaged children and their better-off peers, and reduce the need for costly special education, which can become a repository for students who fall behind early and simply can't catch up with their peers."

With the help of SIF and the Nonprofit Finance Fund, Salt Lake County has been able to build on this important work, launching three new PFS projects in the areas of homelessness, maternal and child health, and criminal justice. We look at these issues in a holistic way, from the data we collect and analyze, to the interventions we apply, to the rigorous evaluation we employ. Our application to SIF highlighted the interconnectedness of our approach:

"Recidivism is an issue that is reaching critical proportions in Utah. A significant portion of offenders have co-occurring substance abuse and mental illness conditions. This category represents 59% of people in prison, 72% of people in jails, and 49% of people on parole versus 25% of the general public. Recidivism rates are significantly higher for this group. There is a gap in treatment programs



for this population. There are programs that treat each of those conditions separately, but not a program that treats them simultaneously.”

Our Pay for Success programs, fueled by SIF, are helping Salt Lake County break the cycle of poverty by providing capital to programs that have proven their efficacy, therefore delivering faster and more effective outcomes for the public.

In addition to supporting Pay for Success programs, SIF is helping to support an ecosystem where capacity is developed at the local level to focus government on outcomes and data. In Utah, SIF funding helped to launch the Policy Innovation Lab as part of the University of Utah’s James Lee Sorenson Global Impact Investing Center within the David Eccles School of Business. In partnership with the private and nonprofit sectors, the Policy Innovation Lab (PIL) will provide funding and other support to highly motivated governments from around the Intermountain West in order to develop innovative, evidence-based interventions that measurably improve the lives of individuals and families in their communities. Recently, the Utah PIL announced the selection of six government agencies to participate in the Social Innovation Fund’s national Pay for Success initiative. These recipients include: The State of Utah’s Governor’s Office of Management and Budget; The State of Colorado, Department of Homeless Initiatives; Adams County School District 50, Colorado; Missoula County, Montana; and the cities of Boise, Idaho and Las Vegas, Nevada.

The Policy Innovation Lab at the University of Utah is responsible for providing technical assistance to these six newly selected sub-grantees. These program funds come with conditions of participation that establish a careful system of checks and balances. It does not merely throw money into social programs with no strings attached and without any evaluation component. Funders, including the government and the private sector, can

rely on measurable outcomes for “success.” This way government funds are reaching those populations most in need by supporting the most effective programs; moreover, the government only makes success payments if the predetermined outcome goals are met. As an intermediary, coordinating among the various parties involved, the Policy Innovation Lab is able to measure the effect of the CNCS funding; this is what makes PIL such a vital, value-added component of the future of Pay for Success in Utah, the western United States, and possibly one day, internationally.

In describing the importance of the Lab’s work with the selected jurisdictions, Mayor Carolyn G. Goodman of Las Vegas, a government selected to participate in the program, stated, “As a longtime education advocate, I understand the importance of high quality early childhood education preparing children academically, socially and emotionally... this is even more critical for low-income families that often lack access to affordable high quality programs. The city of Las Vegas is extremely excited to work with the Utah Policy Innovation Lab and enhance our capacity to increase access to high quality early childhood education, which includes wrap-around services for families living at or below poverty.

SIF has the potential to reinvent how government works. People are tired of the debate between the people who say we need more programs and others say we need less. Where we all agree is that we need to look for ways for government to spend money more efficiently and more effectively. As our mayor, Ben McAdams, declared in this State of the County address earlier this year, “The consequences of failing to measure the impact of our policies and programs go well beyond wasting scarce tax dollars. Every time

a child, or a teenager, or a homeless veteran participates in a program that doesn't work—but could have participated in one that does—that represents a human cost.”

The reality today is that high-impact service providers do not have access to the funding they need. This is primarily due to the fact that government support for social programs is not always tied to results. But it is also because governments tend not to fund the entire cost of a program upfront, leaving service providers with an uncertain and inadequate funding stream.

Pay for Success solves these problems by tapping private funders to provide the full upfront costs of the program and by establishing performance goals that allow government, funders and project partners to measure outcomes and track success over time.

Americans broadly support government spending on social programs to help people most in need in their communities. However, governments need better information about the effectiveness of social programs so they can make informed funding decisions and use taxpayer dollars most effectively. By embracing Pay for Success, governments can deliver improved services on a larger scale to people in need and drive funding toward programs that work best in their communities, without further straining budgets or risking taxpayer money.

Salt Lake County's goal is to deliver better, more effective services for those in need by aligning our resources with data and evaluation. SIF is an invaluable resource in this effort. We urge your favorable consideration of its continued availability.

*Questions or concerns regarding this testimony can be directed to Alyson Heyrend, ([aheyrend@slco.org](mailto:aheyrend@slco.org)) and Patrick Reimherr ([preimherr@slco.org](mailto:preimherr@slco.org)) with the Office of Salt Lake County Mayor Ben McAdams.*

## Charter School Lenders' Coalition

1900 M Street, NW | 2nd Floor | Washington, DC 20036

### TESTIMONY FOR THE HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES REGARDING FISCAL YEAR 2016 APPROPRIATIONS FOR THE CHARTER SCHOOLS PROGRAM

APRIL 29, 2015

As advocates for high-quality public charter schools across the country, the Charter School Lenders' Coalition (CSLC) is pleased to provide written testimony related to the proposed FY 2016 budget and the Credit Enhancement for Charter School Facilities Program (CE Program). The CSLC is a coalition of community development financial institutions (CDFIs) and private, non-profit organizations whose main goal is to provide affordable, flexible capital for the construction of charter schools in low-income communities. To date, the coalition has financed the construction of over 450 charter schools in dozens of states.

We understand that the President's FY 2016 budget contemplates utilizing \$375 million to support charter schools. We welcome this proposed funding increase, and the corresponding commitment to charter schools and our nation's children. As the Subcommittee considers funding, we strongly recommend that you **provide at least 12.5% of the appropriation for public charter schools for facilities**, and that not less than 65% of facilities funding is allotted to the highly successful CE Program.

#### Public Charter Schools Lack Access to Facilities

Though they are public schools, charter schools often do not have access to school district buildings, nor do they generally have access to school facility bond programs operated by local authorities. According to a 2012 survey by the National Alliance for Public Charter Schools, 56% of public charter respondents reported that their current facility will not have adequate space for enrollment in five years. Moreover, unlike traditional public schools, public charter schools must take significant portions of their operating dollars, usually around 20%, and put them toward facilities costs.

#### Credit Enhancement Helps Charters Meet Facilities Needs

The CE Program has done an exceptional job of using its funds to leverage private investment in charter facilities. Since 2002, the program has awarded more than \$255 million to 37 grant recipients, providing credit enhancement to over 500 charter schools in 33 states and the District of Columbia. These awards have leveraged more than \$2.7 billion in financing for charter school facilities, with nearly \$12 in private sector investment for every \$1 in CE Program funding. Approximately half of all the CE investments have supported charter management organization (CMOs), allowing high-performing charters the opportunity to replicate. The other half of CE investments has supported start-ups, or independent charter schools, which are well positioned to design programs to meet the unique needs of students in their communities.

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Bridgeway Capital | Boston Community Capital | Building Hope | Calvert Foundation | California Charter Schools Association | Capital Impact Partners | Charter Schools Development Corporation | City First | Civic Builders | Enterprise Community Partners | Excellent Education Development | Florida Community Loan Fund | Housing Partnership Network | IFF | KIPP Foundation | Local Initiatives Support Corporation | Low Income Investment Fund | New Jersey Community Capital | Nonprofit Finance Fund | Raza Development Fund | Self-Help | The Reinvestment Fund | Uncommon Schools

## Charter School Lenders' Coalition

1900 M Street, NW | 2nd Floor | Washington, DC 20036

### **Federal Support for Credit Enhancement is Key**

Since the inception of charter schools in the early 1990s, the federal government has played a crucial role in spurring the growth of public charter schools. When the Charter Schools Program (CSP) was first established in 1994, there were only 78 schools in seven states. Today, there are approximately 6,400 charter schools in 43 states and the District of Columbia enrolling more than 2.5 million students. Despite this incredible growth, the public charter school sector has not been able to keep up with demand, which is at an all-time high with more than a million students names (an estimated 586,511 individual students) on waiting lists nationwide. These facts underscore why the federal government should continue to ensure that public charter schools grow in quantity and improve in quality.

Once again, we urge your continued support of charter schools and ask that you ensure that at least 12.5% of the total appropriation for public charter schools is available for facilities, and that not less than 65% of facilities funding is allotted to the highly successful CE Program. An appropriation of 12.5% for the CE program, which is in line with both the House and Senate ESEA reauthorization bills, will provide the essential additional program dollars to ensure that high-quality charters have the facility space necessary to accommodate the growing demand for charter schools.

We would be happy to provide additional information related to this issue at the Subcommittee's convenience. For more information, please contact Taimarie Adams, Policy Officer with the Low Income Investment Fund, at 202-677-4285 or [tadams@liifund.org](mailto:tadams@liifund.org).

**Peter Paul Yu, MD, FACP, FASCO**

**President**

**American Society of Clinical Oncology**

**(571) 483-1670**

**Testimony for the Record prepared for:**

**Subcommittee on Labor, Health and Human Services, Education, and Related Agencies,  
United States House of Representatives Committee on Appropriations**

**Regarding funding for the National Cancer Institute and the National Institutes of Health  
for FY 2016**

**April 29, 2015**

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing more than 35,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to provide the following recommendations for Fiscal Year 2016 (FY 2016) funding:

- National Institutes of Health (NIH): \$32 billion
- National Cancer Institute (NCI): \$5.32 billion

ASCO's members set the standard for cancer care world-wide and lead the way in carrying out translational and clinical research aimed at improving the screening, prevention, diagnosis and treatment of cancer. ASCO advocates for policies that provide access to high-quality care for all patients with cancer. ASCO's efforts are also directed toward supporting oncology clinical and translational research that is critical to improving the lives of our citizens and that can inform cancer services for people worldwide.

**The Importance of Federal Cancer Research**

Federally funded cancer research plays a unique and vital role in the field of cancer research. ASCO's annual *Clinical Cancer Advances* report highlights the most groundbreaking cancer research regardless of funding source. Much of the progress in this report and in past reports was made possible by federal investment in clinical cancer research displaying the high quality of federally funded research at the NIH and NCI. In fact, roughly a third of the advances highlighted in this year's report were backed in whole or in part by federal funding from the NIH and the NCI. Some of the most exciting discoveries include:

- Adding chemotherapy to standard advanced prostate cancer treatment yields one of the biggest survival gains ever seen in this disease
- Adding a low-cost hormone treatment to standard chemotherapy helps preserve fertility of young women with breast cancer undergoing chemotherapy and extend their lives
- Adding chemotherapy to standard radiation therapy adds years of life to patients with a class of brain cancers called low-grade glioma
- Identifying ways to maximize benefits and reduce potential risks from low-dose computed tomography (CT) lung cancer screening
- New, molecularly targeted drugs help overcome treatment resistance in lung cancer

For more than 50 years, the NCI has funded many more clinical studies like these, answering critical cancer care questions that would not likely have been pursued by commercial sponsors and might otherwise have been ignored which have resulted in dramatic improvement in survival such as in children with cancer where cure rates of 90% are now common. . But despite this record of success, the future of the US federal cancer research enterprise faces critical challenges that must be addressed by policymakers, together with the cancer community, so that this pace of research progress can continue, or even accelerate.

Federal investment in research has stagnated over the past 10 years, resulting in a 23% loss in purchasing power for the National Institutes of Health. In practical terms, this means promising research is going unfunded, new studies are being scaled back, fewer patients have the opportunity to participate in clinical trials, and future meaningful advances against cancer may be few and far between unless our nation renews its commitment to fighting cancer.

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. Unfortunately, these trials are at risk, due to funding concerns that slow the launch and completion of trials. Of particular concern is the deterioration of NCI support for federally funded trials that take place in community setting where most patients receive their care and where there are very limited alternative research funding opportunities

Clinical trials supported by federal funding have led to important breakthroughs in cancer care, often in areas that industry has no incentive to pursue. Typically, the trial concepts are proposed directly by clinician investigators who based on their direct experiences with patients, hypothesize ways to improve treatments for their patients and seek to test those hypotheses through rigorously designed prospective clinical trials. Just as the NIH RO1 and R21 grant mechanisms inspire researcher creativity and innovation, the National Clinical Trials Network and National Community Oncology Research Program are essential to fostering research initiatives developed by clinician investigators who see firsthand the importance of answering questions important to their patients. Publicly funded clinical trials involve establishing comparative effectiveness, examining promising regimens, optimizing multimodality treatments, developing therapies for rare cancers, and studying prevention and survivorship strategies. These research goals may run parallel to those of commercial sponsors, but publicly funded trials are designed to benefit patients—not intended to achieve regulatory approval or shareholder benefit. Many of these trials are at risk due to funding constraints.

### **Unprecedented Opportunity through the Utilization of Big Data**

Rapid advances in health information technology, including [ASCO's CancerLinQ™](#), have created unprecedented opportunities to collect, analyze and learn from vast amounts of real-world data. Rapid progress is being made in the development and implementation of health information technology (HIT) which will support all forms of research from precision medicine to comparative effectiveness. This promise to help transform how we care for cancer patients and develop new treatments requires standards for data capture, representation, and interoperability. Many NIH and NCI entities are engaged in this area including, the Center for Biomedical Informatics and Information Technology, the Surveillance Epidemiology and End



Results Program, and the National Library of Medicine. Their work is fundamental for an industry that is a growing part of the US economy.

The NIH and the NCI need increased funding to ensure they are poised to operate in a world where big data has the ability to speed the pace of discovery. Without funding necessary to keep up with the pace of progress, federally funded research risks lagging behind in a field where it stands uniquely poised to make advancements for patients.

### **Cancer Panomics – Precision Medicine Realized**

While targeted and individualized treatments already have begun to transform cancer care, our growing understanding of the biology of cancer will take targeted therapy to an entirely new level in the coming decades. Instead of targeting single pathways in cancer cells, we will have the tools to address the panomics of cancer—the complex combination of the molecular characteristics of patients and their cancer that drive the development of each person’s disease, and determine response to therapy and long-term toxicities.

As we move towards this era of cancer panomics, the NIH and NCI first need sufficient funding to ensure completion of President Obama’s proposed Precision Medicine Initiative. The Precision Medicine Initiative could reinvigorate our nation’s leadership in biomedical research and provide clinicians with important new tools and therapies that work best for specific patients. This Subcommittee should ensure full funding of the \$215 million Initiative, including \$70 million for the NCI to develop more and better treatments for cancer. NCI will accelerate the design and testing of effective, tailored treatments for cancer by expanding genomically-driven clinical cancer trials, exploring fundamental aspects of cancer biology, and establishing a national “cancer knowledge network” that will generate and share new knowledge to fuel scientific discovery and guide treatment decisions.

### **Renewing the Commitment**

While we have made great strides in cancer treatment, now is not the time to cut back as cancer impacts more and more Americans. We now have more cancer survivors alive today than at any point in our history and understand more about the diseases that make up cancer than ever before. This is largely because of federal investment in cancer research, but we will not be able to fully harness the opportunities provided by HIT and precision medicine without further investment.

ASCO thanks the subcommittee for its past commitment to cancer research through the appropriations process and appreciates the unique effort made by the subcommittee in this challenging budget environment. We recognize the challenges faced by this subcommittee, but the current path of dwindling investment in cancer research will be devastating to attempts to find future cures.

In order to stop these devastating trends and capitalize on forward progress, the NIH and the NCI must have sustained and predictable increases in funding. While private industry is a strong partner in cancer research, it does not conduct the broad scope of clinical research that is important to cancer patients. The NCI conducts the high risk, high reward research that leads to practice-changing advancements that industry is often unwilling to undertake – such as pediatric applications, direct comparisons of approved drugs, and testing drugs in combination with or prior to radiation or surgical treatments. Progress in fighting cancer would be faster, more efficient, and more sustainable if funding were steady and predictable.

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ASCO again thanks the Subcommittee for its continued support of cancer patients in the US through funding for the NIH and the NCI. We look forward to working with all members of the subcommittee to advance US cancer research.

John Sciamanna, Senior Consultant, Child Welfare League of America

On behalf of the Child Welfare League of America we submit the following statement in support of increased funding under the Child Abuse Prevention and Treatment Act (CAPTA) and the Administration's request for a coordinated demonstration project between ACF and Medicaid.

We request that Congress increase funding for the **CAPTA state grants** at no less than \$30 million and that the Congress increase funding for the **Community-Based Child Abuse Prevention (CB-CAP) grants** at no less than \$42 million.

In addition we request **\$50 million a year under the Administration for Children and Families (ACF)** and **\$100 million a year through the Medicaid program** to create a five-year demonstration involving ACF and CMS to encourage states to implement evidence-based psychosocial interventions to improve outcomes for children and youth in foster care while reducing the over-prescription of psychotropic medications.

This is a very modest increase under CAPTA. For the most part it restores funding eliminated by the recent sequestration cuts. In addition the CAPTA state grant funding level will implement a provision of the 2010 CAPTA reauthorization. In the 2010 reauthorization of CAPTA (PL 111-320), Congress required that if funding exceeds the FY 2009 funding level by \$3 million then the base grant for each state will increase to \$150,000 per state from the current total of \$50,000. Since that reauthorization funding has actually been cut below 2009 levels.

The Child Abuse Prevention and Treatment Act is a historic law that offered national policy and recognition in the need to recognize and prevent of child abuse and neglect. States receive grants to address child abuse prevention and treatment, and while this law is currently the best avenue

the government has to tackle this complex issue, in 2015 the federal government is funding CAPTA at a level of just 32 cents per child per year.

We ask appropriators to make a commitment to at least partially address the decision of authorizers to provide increased minimum grants to states. Last year almost 680,000 children were substantiated as victims of child maltreatment and more than one-third of all victims of child maltreatment do not receive follow up services.

As part of the CAPTA law, the government provides additional support through the Community Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP), yet just like CAPTA, these grants at their current funding of \$40 million a year amounts to just under 50 cents per child per year.

Prevent Child Abuse America estimates that implementing effective policies and strategies to prevent child abuse and neglect can save taxpayers \$80 billion per year. Additionally, the Centers for Disease Control and Prevention determined that the lifetime estimated costs of child abuse totaled \$124 billion and that the cost to one individual survivor was over \$210,000.

The cost of doing nothing incurs direct costs in the future for foster care services, hospitalization, mental health treatment, and law enforcement, while indirect costs include loss of productivity, as well as expenditures related to chronic health problems, special education, and the criminal justice system.

To be more effective, both CAPTA state grants and CB-CAP grants require a substantial increase in funding and a long term commitment to these local community services throughout our country. This appropriations request is a modest first step in that commitment.

The second half of our request is in support of the Administration's FY 2016 budget request includes a five-year joint project between ACF and CMS for competitive demonstration projects to encourage states to implement evidence-based psychosocial interventions targeting children in the foster care system which will help to serve as an alternative to the current over-reliance on prescribing psychotropic medications to this vulnerable population.

The ACF investment of \$250 million over five years would fund state infrastructure and capacity building including:

- o Enhancing the child welfare workforce;
- o Providing valid and reliable screening and assessment tools;
- o Coordinating between child welfare case planning and management and Medicaid, especially Early and Periodic, Screening, Diagnosis, and Treatment (EPSDT);
- o Training child welfare staff, foster parents, adoptive parents, guardians, judges and clinicians;
- o Ensuring fidelity monitoring;
- o Implementing an evaluation; and,
- o Providing data collection and IT systems.

The \$500 million through CMS will provide incentive payments to participating states that demonstrate improvement. A state that receives an incentive payment from this fund cannot use these funds to supplant other funds used by the state to carry out the Medicaid State plan, or IV-B or IV-E of the Social Security Act.

One of the great challenges for children in foster care may be access to adequate and timely health coordination, screening and services. The Administration's proposal attempts to address

not just the over-use of medication but it also attempts to enhance coordination and access to services. The goals of the demonstration include:

- Reduce over-prescription of psychotropic medications, including the elimination of prescribing practices that do not conform to best practice guidelines for children and youth;
- Increase use of evidence-based/evidence-informed, trauma-informed, screening, assessment, and psychosocial interventions as first-line treatments for emotional and behavioral health needs;
- Improve children and youth well-being across physical, social-emotional, cognitive, and developmental domains; and,
- Improve child welfare outcomes including increased child safety, decreased time to permanency, fewer disrupted adoptions, and fewer entries and re-entries into foster care.

Under the proposal HHS would define criteria for qualifying states, qualifying foster children, and recommend models to test. Through a competitive grant process, qualifying states would apply for (1) ACF infrastructure grant funding, (2) incentive payments if they qualify for them based on the Secretarially defined criteria.

We feel these two actions, the beginning of a strengthening of CAPTA funding and the adoption of the President's demonstration project to better coordinate of services between state child welfare and Medicaid agencies will be significant steps forward in services to children and families involved with child welfare and child protective services.

**April 29, 2015**

**FY 2016 written testimony for the record**

I am writing to express my support of funding for individuals who have intellectual and developmental disabilities and who live in community environments rather than institutions. My concern at this moment is that funding for services that support individuals and programs in the community is in jeopardy because of the efforts of those who would rather see that money diverted to institutions.

I am the mother of two grown sons, Nicholas and Adam, who are both severely disabled, both intellectually and physically. During their lives they have lived at home with my husband and me, then moved to an 88-bed facility for disabled children, and for the past several years they have been sharing a two-bedroom apartment in a neighborhood in Norfolk with services they receive under the ID Waiver.

They both are unable to walk, talk, sit up or feed themselves, and they are incontinent. However, they have been living successfully in their own apartment since 2005, supported by Hope House Foundation.

If it weren't for the ID Waiver, I know that my sons would still be living in a medically-based facility with funds going to pay for large overhead costs rather than for the simple, everyday tasks and pleasures that they might only dream of. On the contrary, they are able to live a life that any non-disabled person takes for granted. My husband and I can visit when we want without being restricted by visiting hours and without feeling that we're imposing on other residents' personal space, not to mention that our sons are living in a natural community that supports them physically and socially.

I know that I would not want to be living in an institution myself, and don't know what

my life would be like if I were forced to do so. My sons are happy with their home and I've met many others who don't say "I wish I could move to an institution" but rather, "I want to live in my own place someday". It took a huge effort to help my sons accomplish the life they have today, and I would not want that to be at risk for them or anyone else who desires to live their life as freely and independently as possible.

I wish to reiterate my support for community-based services and hope that you will choose to support my sons and the thousands of others who deserve an amazing and successful life to the extent that they are able.

Thank you,

Pamela Wright  
1620 Bellevue Ave.  
Norfolk, VA



John Sciamanna, Executive Director, National Child Abuse Coalition

On behalf of the National Child Abuse Coalition we submit the following statement in support of increased funding under the Child Abuse Prevention and Treatment Act (CAPTA).

We request that Congress increase funding for the **CAPTA state grants** at no less than \$30 million and that the Congress increase funding for the **Community-Based Child Abuse Prevention (CB-CAP) grants** at no less than \$42 million.

These are very modest increases that for the most part restore funding eliminated by the recent sequestration cuts. In addition the CAPTA state grant funding level will implement a provision of the 2010 CAPTA reauthorization. In the 2010 reauthorization of CAPTA (PL 111-320), Congress required that if funding exceeds the FY 2009 funding level by \$3 million then the base grant for each state will increase to \$150,000 per state from the current total of \$50,000. Since that reauthorization funding has actually been cut below 2009 levels.

The Child Abuse Prevention and Treatment Act is a historic law that offered national policy and recognition in the need to recognize and prevent of child abuse and neglect. States receive grants to address child abuse prevention and treatment, and while this law is currently the best avenue the government has to tackle this complex issue, in 2015 the federal government is funding CAPTA at a level of just 32 cents per child per year.

We ask appropriators to make a commitment to at least partial address the decision of authorizers to provide an increase to states. Last year almost 680,000 children were substantiated as victims of child maltreatment and more than one-third of all victims of child maltreatment do not receive follow up services.

There must be greater attention to both preventative programs and services for children that come to the attention of child protective services.

As part of the CAPTA law, the government provides additional support through the Community Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP), yet just like CAPTA, these grants at their current funding of \$40 million a year amounts to just under 50 cents per child per year.

We know that when we prevent child abuse, it helps prevent Adverse Childhood Experiences (ACEs) that contribute to potentially lifelong physical and mental health issues. Spending on child protective services and on prevention programs supporting healthy child development has not contributed to the growth in the federal deficit. In fact, investing in prevention is less costly to society and individuals than trying to treat problems later.

Prevent Child Abuse America estimates that implementing effective policies and strategies to prevent child abuse and neglect can save taxpayers \$80 billion per year. Additionally, the Centers for Disease Control and Prevention determined that the lifetime estimated costs of child abuse totaled \$124 billion and that the cost to one individual survivor was over \$210,000.

The cost of doing nothing incurs direct costs in the future for foster care services, hospitalization, mental health treatment, and law enforcement, while indirect costs include loss of productivity, as well as expenditures related to chronic health problems, special education, and the criminal justice system.

Child abuse and neglect affects over one million children every year and costs our nation \$220 million every day.<sup>1</sup> Meanwhile, a Government Accountability Office (GAO) study finds that total federal costs of providing initial prevention program funding for low-income populations were offset over four years.<sup>2</sup>

Further, the study also found longer term savings based on the cost reduction of social problems related to abuse,<sup>3</sup> largely due to the fact that abused children have higher rates of juvenile delinquency and special health care needs than those who have not been abused.<sup>4</sup>

Ultimately, increased early funding surrounding child abuse prevention will save taxpayers over the long-term while protecting those children most at risk.

CAPTA includes three important programs the discretionary grants to the states to develop innovative approaches to improve their Child Protective Service (CPS) systems; state grants to support state efforts to improve their practices in preventing and treating child abuse and neglect; and the Community-Based Grants for the Prevention of Child Abuse and Neglect that provides grants to states to support their efforts to develop, operate, and expand a network of community-based, prevention focused family resource and support programs that coordinate resources among a range of existing public and private organizations.

To be more effective, both CAPTA state grants and CB-CAP grants require a substantial increase in funding and a long term commitments to these local community services throughout our country. This appropriations request is a modest first step in that commitment.

Since 1974 CAPTA has been amended many times and its mission of child abuse treatment and prevention has expanded. Unfortunately, its funding has not. When Congress passed CAPTA it helped to establish national standards for specific reporting and response practices for states to include in their existing child protection laws. CAPTA is the only federal legislation exclusively dedicated to the continuum of child maltreatment services and supports, which include preventing, assessing, identifying, and treating child abuse and neglect.

In light of its history, the FY 2015 funding of only 32 cents per child per year means that states are provided only 32 cents to investigate child abuse complaints, to refer and access child abuse

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<sup>1</sup> Gelles, Richard J., & Perlman, Staci (2012). *Estimated Annual Cost of Child Abuse and Neglect*. Chicago IL: Prevent Child Abuse America.

<sup>2</sup> U.S. General Accountability Office. (1992). *Prevention Programs Need Greater Emphasis. Report to the Chairman, Subcommittee on Oversight of Government Management, Committee on Governmental Affairs, U.S. Senate*. (GAO Publication No. GAO/HRD-92-99).

<sup>3</sup> Ibid., 25.

<sup>4</sup> Ibid., 27.

treatment services, 32 cents to screen families and to support families that come to the attention of the child protective services, 32 cents to address new requirements mandated by Congress.

Under CAPTA, in order to be eligible to receive funding states are to have a plan that includes nearly two dozen assurances and elements including the basic requirement to have a system for reporting suspected cases of abuse and neglect, the establishment of mandatory child abuse reporter laws, procedures to assure that child victims in a judicial proceeding is assigned a guardian ad litem who has received training appropriate to the role, and dealing with issues around confidentiality, disclosure and due process.

It is difficult to imagine that the many important and critical elements required by CAPTA including requirements around legal representation, mandatory reporting of child abuse, referrals for safe baby plans and referrals for infant and toddler services can be effectively enforced if minimum allocations are limited to \$50,000 per state.

In more recent reauthorizations Congress has included additional needed practices without including additional funding, such as: policies and procedures to address the needs of infants born with and identified as being affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder; the development of a plan of safe care for the infant born and identified as being affected by illegal substance abuse or withdrawal symptoms or Fetal Alcohol Spectrum Disorder; provisions and procedures for referral of a child under the age of 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under part C of the Individuals with Disabilities Education Act; and policies and procedures that promote collaboration among child protective service agencies, domestic violence service agencies, substance abuse treatment agencies, and other agencies in investigations, interventions, and the delivery of services and treatment provided to children and families affected by child abuse or neglect, including children exposed to domestic violence, where appropriate.

In recent months Congress has added to these requirements with new one around the issue of human trafficking.

The lack of funding through CAPTA limits its enforceability. These conditions have resulted in the Department of Health & Human Services announcing they were repealing regulations for CAPTA because they haven't been updated since 1990.

As part of the CAPTA reauthorization, the Community-Based Child Abuse Prevention were funded at \$40 million, half of the federal authorization cap of \$80 million. The grants support state efforts to develop, operate, and expand a network of community-based, prevention-focused family support programs that coordinate resources among a range of existing public and private organizations. 70% of the funding is distributed to states based on the child population, and the remaining 30% is distributed based on the amount of private, state or other non-Federal funds leveraged from the preceding fiscal year.

The funds are intended to support a range of community based child abuse prevention efforts by targeting a number of vulnerable populations and families. States are required to have a strategy

that assesses local needs, provides a continuum of services, develops local partnerships and involves a number of target populations and service providers.

These grants provide a continuum of preventive services, allow the development of unique approaches and fosters understanding, appreciation and knowledge of diverse populations to address child abuse and neglect prevention efforts in our communities. These funds provide a multitude of services and supports in states.

Community-Based Grants for the Prevention of Child Abuse and Neglect (CB-CAP) are vital to providing funding to promote the prevention of child abuse and neglect and is structured to leverage local and private funds. Investing in prevention is less costly to society and individuals than trying to treat problems later.

We ask Congress to begin a serious effort to fully fund CAPTA by providing no less than this request to increase state grants under CAPTA and to increase state grants under CB-CAP.



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**Public Witness Testimony from the  
American Association for Cancer Research (AACR)  
FY 2016 Appropriations for the National Institutes of Health  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies  
Committee on Appropriations  
United States House of Representatives  
April 29, 2015**

Submitted on behalf of : Margaret Foti, PhD, MD (hc), Chief Executive Officer  
American Association for Cancer Research, 615 Chestnut Street, 17th Floor  
Philadelphia, PA 19106; (215) 440-9300/fax (215) 440-9313; [MaryLee.Watts@aacr.org](mailto:MaryLee.Watts@aacr.org)

The American Association for Cancer Research (AACR) is the world's first and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 35,000 members is to prevent and cure cancer through research, education, communication and collaboration. **The AACR calls on Congress to provide at least \$32 billion for the NIH in fiscal year (FY) 2016 (a minimum of a 5.6 percent increase), and to provide a commensurate increase for the National Cancer Institute (NCI). Putting the NIH and NCI back on a path of sustained and predictable funding growth is the only way we will seize the unparalleled scientific opportunities in cancer research that lie before us, and increased funding is paramount to overcoming the challenges we face in conquering this complex disease.**

We thank the United States Congress for its longstanding, bipartisan support for the National Institutes of Health (NIH) and for its commitment to funding cancer research. We especially thank House Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education Chairman Tom Cole and Ranking Member Rosa DeLauro for their unwavering

support for the NIH, and we appreciate the opportunity to submit testimony on the importance of funding for the NIH and cancer research.

We live in an extraordinary time of scientific opportunity, in which we are rapidly developing the tools necessary to translate basic biological discoveries into therapies that can save and improve millions of lives. Nowhere is this more evident than in precision medicine, an area in which cancer research has been leading the way for more than a decade. If we are to support and foster the goals of the President's Precision Medicine Initiative, a strong commitment to funding medical research is required.

### **Investments in Cancer Research are Saving and Improving Lives**

Significant progress has been made against cancer because of the decades of federal investment in medical research and the dedicated work of researchers, physician-scientists, and patient advocates throughout the biomedical research enterprise. Federal support allows for new and improved approaches to the prevention, detection, diagnosis, and treatment of cancer, and thanks to past investments in basic research, we have never been better positioned to capitalize on our hard-won understanding of what causes and drives cancer. This knowledge of cancer biology is providing the foundation for new treatments and preventive strategies for the more than 200 diseases we call cancer. As is detailed in the [\*AACR Cancer Progress Report 2014\*](#), support from the NIH and the NCI for basic, translational, and clinical research has led to decreases in the incidence of many cancers, cures for a number of these diseases, and higher quality and longer lives for many individuals whose cancers cannot yet be prevented or cured. In fact, the number of cancer survivors living today in the United States is estimated to be more than 14 million. Cancer research also is transforming lives by allowing scientists to advance immunotherapeutic

development, develop new molecularly targeted therapies and consider ways to overcome drug resistance.

The nation's historical investment in cancer research is unquestionably having an impact, and we are seeing results in the form of clinical advances and new treatments. Consider the progress made in just the last 18 months. Cancer patients now have access to:

- 7 new drugs to treat a variety of cancers, including a “first in class” immunotherapy to treat a pediatric cancer;
- 4 new uses for previously approved cancer drugs;
- 1 new cancer screening test; and,
- 1 new cancer prevention vaccine.

The vigorous pursuit of new breakthroughs in cancer research and biomedical science is also serving as one of our country’s primary paths to innovation, global competitiveness, and economic growth. According to United for Medical Research, NIH funding directly and indirectly supported more than 402,000 jobs in 2012 alone, and generated more than \$57.8 billion in new economic activity. These remarkable achievements would never have been possible without a national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies across the federal government. We can continue to make significant advances, but only if we continue to allocate the required resources at the federal level to do so. The NIH and NCI must be put back on a path of sustained, predictable growth this year and in the years to come.

### **Precision Medicine is Re-shaping the Diagnosis and Treatment of Cancer**

A significant milestone for cancer research was the discovery that cancer develops as a result of alterations in the genetic material of cells. Now, thanks to research and technological innovations, it is possible to read every known component of the DNA from an individual's cancer. This groundbreaking approach—treating cancer based on the genetic and molecular profile of a patient's tumor—is often referred to as personalized, or precision, cancer medicine. Under this new paradigm, scientists classify cancers according to the genetic changes that drive them and less by where they originate, such as the breast, brain, lung, or liver. These discoveries also are transforming the detection, diagnosis, and treatment of cancer, and they are leading us future where most cancer treatment and prevention strategies are based on both a person's genetic makeup and the genetic makeup of their specific cancer. Had the federal government not made the wise decision to invest in mapping the human genome, none of this progress would have been possible.

### **Cancer remains a significant public health challenge**

Even in the face of the promise and progress discussed above, cancer remains a formidable opponent. An estimated 1.65 million Americans will be diagnosed with cancer this year, and 1 in every 3 women and 1 in every 2 men will likely develop cancer in their lifetimes. It is also projected that more than 589,000 people will die this year in the U.S. from the disease, which is one person every minute of every day. There also remain a number of cancers, including pancreatic, liver and lung cancers, for which the mortality rate remains extraordinarily high and 5-year survival rates are typically less than 50 percent. Further, racial and ethnic minorities, as well as low-income and elderly populations, continue to suffer disproportionately in cancer incidence, prevalence, and mortality.



Because of the steady increase in cancer incidence rates, which is mainly due to our increasingly aging population and the enormous complexity of many cancers, continuing and strengthening our nation's commitment to cancer research and biomedical science is more critical now than ever. Increasing the federal investment in cancer research and biomedical science will play a vital role in addressing the current challenges in cancer, while at the same time curbing the overall annual costs of this devastating disease —the economic burden of which exceeded \$263 billion in 2010 and is expected to continue to rise as the number of cancer deaths increases.

### **Progress against cancer requires a sustained commitment to funding**

Our nation's ability to realize the exciting future that awaits us in cancer research depends on a strong commitment by Congress to provide sustained, predictable funding increases for the NIH and the NCI. As a country we must set priorities at this difficult time in our history—and the government can do no better with its money than continue to invest in medical research. We are in a defining time in America's commitment to finally defeat cancer. We must seize the opportunity to invest our nation's remarkably productive medical research ecosystem **by providing at least \$32 billion for the NIH in FY 2016 and enable the NIH to fund important programs such as the Precision Medicine Initiative.** This investment will ensure we can continue to transform cancer care, spur innovation and economic growth, maintain our position as the global leader in science and medical research, and most importantly, bring hope to patients and their loved ones everywhere.

The AACR looks forward to working with you to ensure that researchers have the resources they need to continue to deliver hope to those who are confronting this dreaded disease.



UNITED STATES HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES

WRITTEN TESTIMONY  
SUBMITTED BY  
JOHNNY C. TAYLOR, JR., PRESIDENT & CEO  
THURGOOD MARSHALL COLLEGE FUND  
APRIL 29, 2015

INTRODUCTION

Thank you Chairman Cole and Ranking Member DeLauro and the entire Committee for accepting this written testimony. My name is Johnny C. Taylor, Jr., President and CEO of the Thurgood Marshall College Fund (TMCf). More than eighty percent of all students enrolled in HBCUs attend TMCf member schools. TMCf supports and represents more than 300,000 students attending the country's 47 *publicly-supported* Historically Black Colleges and Universities (HBCUs), medical schools and law schools. TMCf was established in 1987 under the leadership of Dr. N. Joyce Payne. It is with a sense of urgency that I submit written testimony to highlight TMCf's FY 16 education budget priorities and highlight the importance of increasing critical funding streams that support Historically Black Colleges and Universities (HBCUs). Specifically, our priority programs under the Labor HHS Appropriations Subcommittee include Title III B: Strengthening Historically Black Colleges and Universities; Pell, and the Capital Financing Program. As you deliberate the FY 2016 budget, we urge the Committee to appropriate \$267 million in discretionary funding and \$85 million in mandatory funding for Title III, Part B programs. Additionally, approve \$61 million for the HBCU Graduate Institutions Program (HGBI) and restore

funding for the Master's degree program to the \$11.5 million FY 2012 level. We also request that the Committee consider an increase in Pell funding to \$22.8 billion and an increase to \$25 million for the HBCU Capital Financing. These programs are administered by the Department of Education.

As demographics change, HBCUs provide access and opportunities to an increasingly diverse population and remain committed to preparing America's future leaders in education, science and technology, law, medicine and public service to meet the workforce demands in a globally competitive world. In an effort to ensure that we are producing a pipeline of top talent, critical funding and other resources targeted to HBCUs must be preserved. We urge the committee to increase funding for priority HBCU programs and accounts to ensure students attending HBCUs have the resources to ensure they graduate with the skills and knowledge to be globally competitive.

#### **Enhance Title IIIB: Aid for Institutional Development**

##### *Title IIIB: Strengthening Historically Black Colleges and Universities (Section 323)*

TMCF urges the Committee to maintain and consider increasing the FY 16 discretionary and mandatory funding levels for Title IIIB, Strengthening Historically Black Colleges and Universities program. This account has not kept up with inflation and sequestration resulted in real cuts to individual campuses. Please restore Title IIIB discretionary funding to FY 2010 levels of \$267 million. The account is currently funded at \$227 million. Additionally, please protect the \$85 million mandatory funding for FY 2016.

<b>Title III, Part B Discretionary (Section 323)</b>	
FY 2004	\$275,863,744
FY 2005	\$238,576,000
FY 2006	\$238,095,000

FY 2007	\$238,095,000
FY 2008	\$238,095,000
FY 2009	\$238,095,000
FY 2010	\$265,624,000
FY 2011	\$236, 991,068
FY 2012	\$227,980,000
FY 2013	\$216,381,000
FY 2014	\$223,800,000
FY 2015	\$228,000,000

An increase in funding levels for the Title IIIB programs are critical to enhance and sustain the quality of HBCUs and to meet the national challenges associated with global competitiveness, job creation and changing demographics. In particular, these funds support research opportunities for STEM students and professional development for faculty in the science and technology fields. These funds are also used to help build endowments.

*Title III, Part B, Strengthening Historically Black Graduate Institutions (Section 326)*

TMCF argues the Committee to approve \$61 million for the HBCU Graduate program under Title IIIB, section 326. This would essentially result in a \$2 million increase from FY 2015.

*Title VII, Masters Degree Programs at HBCUs and PBIs*

The Master's Degree Program for HBCUs was last funded under the FY 2014 budget at \$11.5 million. We ask the Committee to please restore funding for this account to match the FY 2012 enacted level.

### **Increase Pell and Reinstate Summer Pell**

We respectfully request that the Committee approve \$22.8 billion for the FY 16 Pell funding level. TMCF supports a \$5,690 maximum Pell award. We also urge the Committee to reinstate summer Pell Grants.

To date, TMCF has provided more than \$200 million in scholarships, programmatic and capacity building support to students and member schools. The average in-state tuition at a TMCF school is \$7,105 and is a desirable choice for diverse first generation college students. While the tuition rates of our member schools remain reasonable, the resources from key accounts across the federal government established to support students, HBCUs and minority serving institutions continue to shrink and jeopardize the likelihood of students obtaining a college degree. This is a national security issue.

The majority of students who attend HBCUs depend on some form of financial aid to complete their degree. Of all first-time, full-time undergraduate degree/certificate-seeking students who attend TMCF member-schools, 93% rely on financial aid in pursuit of a degree. While HBCUs provide a quality affordable education, many low-income families continue to debate the return on a college investment when they are required to take out large amounts of loans. Year round Pell makes it possible for many first-generation students to complete college on time. As a nation, we want to provide as many avenues as possible for low-income students to enter and complete college with minimal amounts of college loan debt.

Though there have been modest increases in Pell, these increments have failed to keep up with inflation, caused a decline in enrollments at HBCUs and hindered many students from persisting and graduating. More should be done to ensure students entering college graduate with a degree and are prepared for the globally competitive workforce. This is a national security issue.

Traditionally, HBCUs have accepted first-generation, low-income students who often graduate from poor performing high schools and on average take longer to complete college. As a result, these students often attend HBCUs during the summer before their freshman year to get a jumpstart. Additionally, first generation students who attend summer school are more likely to complete their degree on time. Year-round Pell should be reinstated.

**HBCU Capital Financing Program**

TMCF urges Congress to increase the HBCU Capital Financing program by \$5.6 million resulting in a \$25 million funding level for FY 16. This program provides low-cost capital to finance physical improvements on HBCU campuses by guaranteeing and administering loans. At a minimum, we recommend restoring the loan subsidy to the pre-sequester level of \$20.5 million. We also request appropriations language to remove the \$1.1 billion loan guarantee statutory cap.

Thank you for your consideration of TMCF's funding proposals. Please let me know if you have questions or would like to meet in the future to discuss TMCF's FY 16 funding recommendations.

**Person Submitting Testimony:** Mary Anne Harvey, Executive Director, Disability Law Colorado, [maharvey@DisabilityLawCO.org](mailto:maharvey@DisabilityLawCO.org), (303) 722-0300

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LL.Approp@mail.house.gov](mailto:LL.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of Disability Law Colorado, the Protection and Advocacy (P&A) agency for Colorado on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, Disability Law Colorado served 118 individual clients, held 11 trainings with 978 people trained, and provided informational and referral services to an additional 444 people.

In addition to these activities, 180,000 people were impacted by the activities undertaken by Disability Law Colorado on behalf of groups of clients. These activities benefited individuals in every state and territory in the United States.

As an example of the work done by Disability Law Colorado concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

Disability Law Colorado was successful in helping to move a 23-year-old woman with developmental disabilities out of a nursing home where she had been residing for nearly 18 months. During the process the advocate was also successful in increasing the availability of accessible and affordable housing for people with developmental disabilities. The local public housing authority had a representative on the planning team. At the request of the housing authority staff person, our advocate wrote a letter of support to the housing authority board, which approved up to 10 vouchers per year for people to receive preferential points to move from institutions or nursing homes into the community. The preferential points will move them to the top of the list so as soon as housing is available, they will be able to move.

Disability Law Colorado was also successful in moving a woman with developmental disabilities who had been placed in a nursing home for rehabilitation to a less restrictive group home while she recovered from hip surgery.

In 2009 the Governor announced the closure of the skilled nursing unit at the Regional Center in Grand Junction. Disability Law Colorado learned that there were 32 residents of



that unit and that they were to be moved out of the skilled nursing unit and into nursing homes. Disability Law Colorado contacted the state and made it clear that moving these individuals into nursing homes was unacceptable. Working cooperatively with the Regional Center staff, Disability Law Colorado ensured that an attorney or advocate attended each transition planning meeting for each resident, participated in a community task force to oversee the transition, visited potential placements for the residents prior to placement, and made follow-up visits to the placement once the resident had moved. This support helped allay fears of family members that their relative would be “dumped” in the community and ensured that the transitions were carefully planned. Significantly, the local developmental disabilities service agency was successful in building community-based group homes in Grand Junction for a number of the residents. Only one of the 32 residents moved into a nursing home. That placement was unique because she was from the San Luis Valley, her mother lived in the same nursing home, and her sister lived in that community.

Disability Law Colorado has had a significant role in deinstitutionalizing people with developmental disabilities in Colorado, and today we estimate that there are less than 100 people still living on the grounds of Colorado's Regional Centers. In the last several years our work has focused on individuals with developmental disabilities under the age of 50 who are living in nursing homes and who would like to move.

Thank you for this opportunity to submit this testimony.

**FY 2016 Written Testimony of**

John H. Noseworthy, M.D., President and Chief Executive Officer, Mayo Clinic

**Submitted to:**

**U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

The Honorable Harold Rogers, Appropriations Committee Chair  
 The Honorable Nita Lowey, Appropriations Committee Ranking Member  
 The Honorable Tom Cole, Subcommittee Chair  
 The Honorable Steve Womack, Subcommittee Vice Chair  
 The Honorable Rose DeLauro, Subcommittee Ranking Member

April 29, 2015

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**Introduction.** On behalf of the Mayo Clinic, thank you for the opportunity to submit testimony regarding Fiscal Year (FY) 2016 appropriations. For the reasons enumerated below, **Mayo requests no less than \$32 billion in FY 2016 funding for the National Institutes of Health (NIH).** NIH-funded research is an essential national investment that increases understanding of human disease, spurs the development of novel diagnostics and therapies, and uncovers new strategies to prevent disease and to improve health. Because NIH is the largest source of biomedical research funding not only in the United States but also in the world, the failure of NIH funding to keep pace with medical inflation decreases support for and the conduct of basic research; inevitably, this compromises the realization of those crucial scientific breakthroughs that enhance health, lengthen life, and reduce disease and disability. “Important secondary benefits of medical research such as job creation, regional and global economic activity,

international competitiveness, intellectual property and commercializable products are likely adversely impacted as well.”<sup>1</sup> While NIH funding is certainly not Mayo’s only Labor-HHS funding priority, it is on behalf of these research efforts that we focus on NIH funding in our testimony today.

**Background.** Mayo Clinic is headquartered in Rochester, Minnesota, has facilities in six states, and provides care for more than one million people annually from all 50 states and 135 countries around the globe. The Mayo Clinic ethos has always been to provide the best care to every patient every day through integrated clinical practice, education and research. One of Mayo Clinic’s founders, William J. Mayo, M.D., stated: “The best interest of the patient is the only interest to be considered.” That primary value – the needs of the patient come first – has guided Mayo’s practice throughout our 150-year history.

**Importance of Research at Mayo Clinic.** In addition to clinical care, Mayo has a robust research program, and we believe that exceptional research drives exceptional patient care. This “bench to bedside” is a hallmark of Mayo’s three shields—symbolized by its logo of three interlocking shields, demonstrating Mayo’s commitment to excellence and interdependence in the three areas of clinical practice, research and education. Mayo Clinic conducts basic, translational, clinical and epidemiological research at its campuses in Arizona, Florida and Minnesota and throughout Mayo Clinic Health System. As doctors treat patients and see opportunities for advancing patient care, they work together with Mayo scientists and research teams to develop new and improved diagnostic tools, medications, devices, treatment protocols

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<sup>1</sup> FY 2016 Budget Justification, NIH.

and more. Mayo Clinic's unique culture of collaboration and teamwork, and its extensive facilities and resources, make it possible for researchers to unravel and solve complex research questions. Funding from NIH has contributed to groundbreaking research at Mayo Clinic that has yielded novel therapies and/or assessment tools for a wide array of conditions including vasculitis, lymphoma, motility disorders of the gut, and Alzheimer's disease to name just a few. NIH funding accelerates the work of Mayo's physicians, researchers and scientists to find answers for patients.

**Biomedical Research—the Big Picture.** The NIH budget over the past decade has consistently trailed behind the rising costs of conducting medical research.<sup>2</sup> Cuts to government-funded medical research will have long-term deleterious effects on the health care system and the economy while a strong investment in biomedical research will lead to a stronger financial picture in the United States. For example, researchers have suggested that a 1% reduction in cancer-related mortality could save \$500 billion.<sup>3</sup> Recent research referenced in the *New England Journal of Medicine* revealed inadequate funding for scientists working in the U.S., and this has coincided with a decline in the number of funded NIH grant applications—from 31% in FY 2002 to 19% in FY 2010.<sup>4</sup> In addition to its effect on our economy, a commitment to biomedical research funding has a direct effect on patients' lives. The commitment to research at Mayo Clinic has directly improved patient health outcomes in numerous ways. For example, a direct contribution of Mayo research that was funded, in part, with NIH dollars is a novel

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<sup>2</sup> Gordon H. Sum, MD *et al.*, "The Calculus of National Medical Research Policy – The United States Versus Asia", *New England Journal of Medicine*, August 23, 2012, pp. 687-690

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

imaging technology for detecting organ fibrosis—a safer and less expensive alternative to tissue biopsy.

**History of NIH Funding.** As noted by the Association of American Medical Colleges (AAMC) in its recent FY 2016 written testimony, the NIH budget remains lower than it was in FY 2012 in actual dollars, and since 2003, NIH funding has decreased by 23 percent after adjusting for biomedical inflation. These statistics need to change. As AAMC also noted, almost 84 percent of the NIH’s budget is competitively awarded through more than 55,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions across the country. This includes Mayo Clinic, and this crucial funding supports life-saving and life-improving research at our facilities and others throughout the nation.

**Translational Research.** Translational research occurring every day at Mayo Clinic has a direct link to clinical outcomes. For example, Mayo scientists discovered a class of drugs called ‘senolytics’ that selectively kill senescent cells. Targeting senescent cells may enhance lifespan and delay, alleviate, prevent, and/or treat age-related chronic disease and disability as a group, instead of one at a time.<sup>5</sup> This research would not have been possible without NIH funding. Additional examples of Mayo Clinic research funded, in part, by NIH that has had a direct impact on clinical outcomes include: the development of novel peptide-based drugs for a new therapeutic approach to heart failure and hypertension; the development of proper procedures and protocols that reduce mortality from myocardial infarction (heart attack); using

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<sup>5</sup> Yi Zhu *et al.* “The Achilles’ heel of senescent cells: from transcriptome to senolytic drugs”, *Aging Cell*, March, 7 2015, pp. 1-15

pharmacogenomics (the impact of genetic variation on drug responses) as a way of devising novel therapies for breast cancer.

As stated the portfolio of NIH sponsored research is expansive and critical to the future of discovery and innovation. We highlight one example of critical NIH initiatives for which continued, robust funding is essential – the Specialized Programs of Research Excellence (SPOREs). The SPORE program is housed within the Translational Research Program (TRP), part of the National Cancer Institute (NCI). According to the agency, SPOREs are “the cornerstone of NCI’s efforts to promote collaborative, interdisciplinary translational cancer research.” SPORE grants support projects that will result in new and diverse approaches to the prevention, early detection, diagnosis and treatment of human cancers. At Mayo Clinic, a SPORE grant helped fund research that contributed to a rekindled interest in a class of drugs known as PARP inhibitors to treat cancer, and their recent regulatory approval in fall 2014 to treat ovarian cancer in the U.S. and Europe. Without Mayo’s ovarian SPORE grant from NIH, this breakthrough likely would not have been possible.

**Conclusion.** As a worldwide leader in medical care, research and education, and through its integrated clinical practice, education, and research, Mayo Clinic’s mission is to provide the best care to every patient and to inspire hope for patients with challenging diseases. A commitment to and support for biomedical research are indispensable in meeting both objectives. We strongly urge the committee support at least \$32 billion in funding for NIH in FY 2016, and that specific, meritorious funding programs, such as SPORE funding, be protected in the FY 2016 Labor-HHS appropriations bill.

**STATEMENT  
of the  
American Association of Neurological Surgeons  
and the  
Congress of Neurological Surgeons  
to the  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Committee on Appropriations  
U.S. House of Representatives  
RE: FY 2016 Funding for Trauma and Emergency Care Programs  
April 29, 2015**

The American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS) **strongly urge Congress to appropriate \$28 million for fiscal year 2016 for Parts A-D and H of Title XII of the Public Health Service Act (PHSA).** The PHSA (Sections 1201-4, 1211-22, 1231-32, 1241-46 and 1281-2) authorizes a total of \$248 million in funding for trauma and emergency care programs and activities. These provisions of law have historically received strong bipartisan support.

The request for the total of \$28 million would include funding for these programs as follows:

- \$11 million for Trauma Care Center Grants.<sup>1</sup> Authorized at \$100 million per year, this program would support federal grants to trauma centers to provide operating funds to maintain their core missions, compensate for losses from uncompensated care and provide emergency awards to centers at risk of closure.

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<sup>1</sup> Trauma Center Grants were first authorized as Part D of Title XII of the PHSA by P.L. 102-321 in 1992; and reauthorized by P.L. 111-148 in 2010

- \$11 million for Trauma Service Availability Grants.<sup>2</sup> Authorized at \$100 million per year, this program would provide states financial resources to address shortfalls in trauma services and improve access to care.
- Trauma and Emergency Care Systems Grants.<sup>3</sup> This program includes the following funding requests:
  - \$3 million for Trauma Systems Planning Grants to support state development of trauma systems.
  - \$3 million for Regionalization of Emergency Care Pilots for pilot projects to design, implement and evaluate innovative models of regionalized emergency care systems. Coordinated emergency medical and trauma systems within a region are critical for improving patient health outcomes, including for patients suffering a stroke, heart attack, or other cardiac emergencies where time is of the essence in treatment.

Funding for these programs will help improve access to life-saving trauma and burn care, prevent more trauma center closures and will help develop regionalized systems of emergency care to promote greater efficiency of emergency medical and trauma care.

***Funding Justification: Trauma is a public health problem***

The ability to deliver trauma care services — comprehensive, specialized treatment to victims of blunt force or penetrating injuries, as well as burns — within an hour of injury is critical to

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<sup>2</sup> Trauma Service Availability Grants were first authorized as Part H of Title XII of the PHSA by P.L. 111-148.

<sup>3</sup> Trauma Care Systems Grants were first authorized in Part A of Title XII of the PHSA by P.L. 101-590; most recently reauthorized by P.L. 111-148 with the addition of Regionalization of Emergency Care Systems.



survival. Such traumatic injuries are a significant driver of health care costs. In fact, in the United States, approximately 35 million people are treated every year for traumatic injuries<sup>4</sup> — which includes one hospitalization every 15 minutes. Each year, approximately 500,000 people receive medical treatment for burns, 30,000 are hospitalized in burn centers, 4,300 fire fighters suffer burn injuries and 3,400 people die from fire or burn-related injuries. And, at a cost of \$56.7 billion in 2012, trauma was the most costly medical condition for adults 18-64, followed by cancer at \$52.7 billion, mental disorders at \$51.1 billion, and heart disease at \$45 billion.<sup>5</sup> Despite these facts, the federal investment in ensuring access to life-saving trauma care for all Americans is woefully lacking.

PHSA trauma programs are designed to ensure the availability and effective use of trauma care to save lives, costs and improve patient outcomes. Trauma can happen to anyone, anytime and anywhere. As demonstrated by the numerous lives saved following the bombing at the Boston Marathon and other recent mass casualty events, getting the severely injured to a Level I or II trauma center within the first "golden hour" is paramount. Yet, trauma centers struggle to keep their doors open. Trauma will continue to occur, despite the best prevention efforts. Unfortunately, access to trauma care is threatened by losses associated with the high cost of treating severely injured patients, including those unable to pay for their care, as well as a growing shortage of physicians who take care of trauma patients (e.g. trauma, neurological and orthopaedic surgeons).

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<sup>4</sup> National Trauma Institute. [www.nationaltraumainstitute.com](http://www.nationaltraumainstitute.com). San Antonio, TX.

<sup>5</sup> Soni, A. Top 5 Most Costly Conditions among Adults Age 18 and Older, 2012: Estimates for the U.S. Civilian Noninstitutionalized Population. Statistical Brief #471. April 2015. Agency for Healthcare Research and Quality,

The PHSA trauma programs should be funded because federal investments in trauma systems and centers are prudent to improve patient outcomes and provide downstream cost savings. The availability of specialized trauma centers and their effective use through coordinated trauma systems has a close correlation with improvements in mortality and other quality measures. Seriously injured victims treated in Level I trauma centers have a 25 percent lower risk of death, as well as improvements in one-year physical functioning — particularly for those patients with severe lower extremity injuries.<sup>6</sup> Mortality increases 3.8 times if the severely injured patient is treated initially at a non-trauma hospital instead of bypassing that facility for initial resuscitation at a Level I Trauma Center. Many traumatic injuries lead to lengthy and potentially expensive recuperative and rehabilitative services. Trauma center services improve the efficiency of this subsequent care by reducing the utilization of subsequent services. Effective trauma systems ensure the severely injured are treated at higher level centers, and the less severely injured can be treated at lower cost trauma centers.

Consider the following key facts supporting need for funding PHSA Trauma Programs:

- Traumatic injury is the leading cause of death under age 44;
- Trauma is costly condition at \$56.7 billion per year for adults 18-64;
- Top mechanism of injury (40 percent) are falls — primarily elderly and children;
- 25 percent reduction in mortality for severely injured trauma patient receiving care at a Level I Center;
- 20 percent reduction in the risk-adjusted odds of death in the state with an established

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Rockville, MD. [http://mecps.ahrq.gov/mecpsweb/data\\_files/publications/st471/stat471.pdf](http://mecps.ahrq.gov/mecpsweb/data_files/publications/st471/stat471.pdf).

<sup>6</sup> MacKenzie, et al., “A National Evaluation of the Effect of Trauma Center Care on Mortality,” *The New England Journal of Medicine* (January 2006): 366-378.

trauma system;

- 35 million Americans are treated annually for trauma — one hospitalization every 15 minutes;
- From 1990-2005, 30 percent of trauma centers closed; and
- 45 million Americans lack access to Level I trauma centers within the golden hour.

### *Conclusion*

The "value" proposition for trauma care is well documented. The care provided by trauma and burn centers, their specialist physicians and the supporting trauma and burn team has a dramatic impact on subsequent quality of life and is delivered in a cost efficient manner. In fact, trauma center care is more cost effective than many other interventions, including dialysis for kidney failure.

The immense economic pressures facing trauma centers that struggle to stay in operation are escalating. Lack of adequate funding is a significant factor in many trauma center closures. We have seen 30 percent of trauma centers close in a 15-year period, including the primary trauma hospital treating 848 trauma victims on 9/11.

As the House Labor-HHS-Education Appropriations Subcommittee makes difficult choices to prioritize the most prudent federal investments, we urge \$28 million in funding to be included to implement the PHSA trauma and emergency medical services programs.

Thank you for considering our request.

Rachel Gandell, Chair, Friends of NICHD  
 Subcommittee on Labor, HHS, Education, and Related Agencies  
 National Institutes of Health, National Institute of Child Health and Human Development

On behalf of the Friends of *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), I urge the Labor-HHS-Education-and-Related-Agencies Appropriations Subcommittee to support at least \$32 billion for the National Institutes of Health (NIH), including \$1.37 billion for NICHD for FY16. Our coalition includes over 100 organizations representing scientists, health care providers, patients and parents concerned with the health and welfare of women, children, families, and people with disabilities.

NICHD has achieved great success meeting the objectives of its broad biomedical and behavioral research mission, including research on child development before and after birth; maternal and child health; learning and language development; women's health and reproductive biology; population issues; and medical rehabilitation. With sufficient resources, NICHD can build upon the below initiatives, producing new insights and solutions benefitting women, children and families in your districts.

**Preterm Birth:** NICHD supports research to study the causes, prevention and treatment of preterm birth. Preterm birth, a leading cause of infant mortality and intellectual and physical disabilities, costs \$26 billion annually. Continued prioritization of extramural prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network and intramural research are necessary. Per NICHD's Scientific Vision, support for transdisciplinary science is needed to study and identify the complex causes of prematurity.

**National Children's Study (NCS)/Strategic Pediatrics Research:** The NCS, created by the 2000 Children's Health Act (CHA) to evaluate environmental influences children, was, after years of effort and public investment, deemed unfeasible and closed. However, the child health goals of the CHA are still vitally important. The President's FY16 budget includes \$158 million for the NIH Office of the Director for Strategic Pediatrics Research to succeed the NCS. We

support this and urge NIH, with NICHD input and participation, to conduct innovative pediatric research beginning in the prenatal period to determine the effects of physical and social environments on child health. We also support the President's request for \$7 million to maintain and provide researcher access to data and biospecimens collected during the NCS pilot phase.

**Contraceptive Research:** The Contraceptive Discovery and Development Branch supports basic, applied and clinical research. NICHD plays a key leadership role in addressing behavioral issues related to fertility and contraceptive use. Other foci include evaluation of the safety and effectiveness of hormonal contraception for overweight or obese women. NICHD's investment is also critical for producing new modalities that are more effective, affordable, acceptable, and easier to deliver. Opportunities in this area include the need for non-hormonal contraception, pericoital contraception, and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

**Reproductive Sciences:** NICHD researches innovative medical therapies and technologies and improves existing treatment options for gynecologic conditions affecting overall health and fertility. This research focuses on serious conditions that have been overlooked and underfunded, despite the fact that they impact many women. Future work could focus on infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids.

**Pelvic Floor Disorders Network (PFDN):** Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting 25% of American women. The PFDN conducts research to improve treatment of these painful gynecological conditions. Current research aims to improve female urinary incontinence outcome measures and ensure high quality outcomes.

**Research Workforce:** Adequate levels of research require a robust research workforce. The years of training combined with funding uncertainty are disincentives for students considering a biomedical research career. E.g, there is a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. The Women's Reproductive Health Research and Reproductive Scientist Development Programs enable ob-gyns to further their education and experience in basic, translational, and clinical research, and provide training grants. Continued investment in these and similar programs is critical.

**Population Research:** The Population Dynamics Branch supports research on how population change affects the health, development, and wellbeing of children and their families. It supports large studies, such as the National Longitudinal Study of Adolescent to Adult Health, a survey of over 20,000 adolescents followed for 15 years into adulthood. Such datasets enable scientists to understand how genetic, biological and social factors interact to influence child health and development.

**Sex Differences in Research:** We encourage NICHD to increase data reporting to address gaps in gender and sex differences in research. In addition, sex differences should be included as part of the design of all basic biological studies and clinical research. If the researchers were to consider sex differences in the design of basic science and clinical studies, more appropriate conclusions could be drawn, and clinical research would provide more representative data on safety and efficacy of drugs.

**Clinical Trials in Pregnant Women:** Pregnant women have historically been excluded from most research trials due to concern that participation could harm the fetus. Although there is substantial progress in including women in federally funded research, pregnant women are still excluded, even from research that would advance our knowledge of medical conditions and

treatments in pregnancy. Mindful of the important considerations of research on pregnant women, we support establishment of a federal work group to propose how research might be done appropriately in this area.

**Pediatric Enrollment Data in NIH Trials:** NIH policy mandates inclusion of women, minorities, and children in clinical studies whenever appropriate. Yet, unlike for women and minorities, NIH does not collect children's enrollment data. We urge NIH, with NICHD leadership, to track the numbers of children, broken down by age group, enrolled in NIH-funded studies to ensure adequate child representation in relevant trials.

**Mother-Infant Relationships:** NICHD supports multidisciplinary, cutting edge research to advance understanding of attachment in mother-infant relationships and its impact on development. Early life experiences can have profound impacts later in life, but often require specific experimental controls to pinpoint various factors. We urge NICHD to continue intramural and extramural research on the complex interaction of behavioral, social, environmental, and genetic factors, to improve understanding of and interventions for mental illnesses such as depression, addiction, and autism.

**Best Pharmaceuticals for Children Act (BPCA):** NICHD, through the BPCA, funds study of drugs important to children but which have been inadequately studied in children. We urge continued funding for this and for training the next generation of pediatric clinical investigators.

**Rehabilitation Science:** The National Center for Medical Rehabilitation Research (NCMRR) currently resides in NICHD, yet the stature of NCMRR needs to be raised. We recommend moving the NCMRR to an independent Institute or Center reporting directly to the NIH Director, or to establish a new Office of Rehabilitation Research in the Office of the NIH Director. This requires a statutory change. NCMRR elevation is a critical step in achieving enhanced

coordination of rehabilitation science across all the Independent NIH Centers that conduct and support this research.

**Down Syndrome:** NICHD-funded investigators have made unprecedented progress toward identifying treatments to reverse or ameliorate the cognitive impairment associated with Down syndrome, and understanding how a gene on the 21<sup>st</sup> chromosome may contribute to the development of Alzheimer's in people with Down syndrome. The Down Syndrome Registry, DS Connect, has also allowed the Down syndrome community to share information and health history in a safe, confidential, online database.

**Intellectual and Developmental Disabilities Research Centers (IDDRC):** IDDRCs have greatly improved understanding of the causes of developmental disabilities and developed effective treatments consistent with their mission. We are however concerned that the IDDRCs do not have sufficient resources to sustain this progress. We urge additional resources for research infrastructure and expansion of cores, so that they can conduct research to develop effective prevention, treatment and intervention strategies.

**Human-Animal Interaction:** NICHD plays an essential role in human-animal interaction research. 65% of US households include a pet. There is growing evidence of the health benefits of pet ownership. The bond between humans and animals can impact the health and development of children, from strengthening early childhood immune systems to mitigating childhood obesity to improving mental health. Research on the benefits of animal-assisted therapy for children with autism spectrum disorder and other conditions relies on the NICHD human-animal interaction research program and should continue.

Thank you for your consideration and we look forward to working with you on these critical issues.





**Statement for the Record**

**Prepared by Ellie Hollander, President and CEO, Meals on Wheels America  
Submitted to the Subcommittee on Labor, Health and Human Services, Education and  
Related Agencies  
Committee on Appropriations, U.S. House of Representatives**

**Public and Outside Witness Hearing**

**April 29, 2015**

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to present testimony concerning Fiscal Year (FY) 2016 appropriations for Older Americans Act Nutrition Programs administered by the Administration for Community Living/Administration on Aging within the U.S. Department of Health and Human Services. On behalf of Meals on Wheels America and the more than 5,000 local, senior nutrition programs and the individuals they serve, we are grateful for your past and continued support for these vital programs. As your Subcommittee crafts and considers the FY 2016 Labor-HHS-Education Appropriations Bill, we urge you to adopt the funding levels provided in the President's FY 2016 Budget Request to Congress at a total of \$854.6 million. Specifically, for the three Older Americans Act (OAA) Nutrition Programs authorized under Title III of the Act, that request is as follows:

- Congregate Nutrition Services (Title III, C-1) – \$458,191,000
- Home-Delivered Nutrition Services (Title III, C-2) – \$236,397,000
- Nutrition Services Incentive Program (Title III, NSIP) – \$160,069,000

Furthermore, we support the Administration's request for \$20 million for Nutrition Innovation Demonstrations. If enacted, this funding would support proven innovations and an opportunity to develop a perfected and scalable nutrition services model to optimize healthcare savings and quality of life for the seniors served.

At this critical juncture in our nation's history, when both the need and demand are already substantial and will continue to climb exponentially, we implore you to give this request your utmost consideration due to the significant social and economic benefits that OAA Nutrition Programs offer. The nutritious meals, friendly visits, and safety and wellness checks these programs deliver each day are providing an efficient, effective and critical support service for our most vulnerable seniors, our families, our communities, and taxpayers as a whole. OAA Nutrition Programs (both congregate and home-delivered) enable seniors to live more nourished and independent lives longer in their own homes, reducing unnecessary visits to the emergency room and premature hospitalization and institutionalization. They are not only providing more than a meal to those who are fortunate to receive their services, but they are also an essential part of the solution to our nation's fiscal and demographic challenges.

For nearly 50 years in communities large and small, urban and rural, OAA Nutrition Programs have been successfully serving our nation's seniors in greatest economic and social need. This expansive network of 5,000+ Meals on Wheels programs is serving every state and district across the country. And the federal dollars authorized under Title III of the Act are a pivotal foundation on which to support their operational infrastructure and leverage additional state, local and private resources to serve more seniors who are frail, isolated, and at significant risk of hunger and losing their ability to live in their home. Data from the most recent Administration on Aging's State Program Reports (2012) and National Survey of OAA Participants (2013) demonstrates that the seniors receiving meals at home and in congregate settings, such as senior centers, need these services to remain healthier and more independent. They are primarily women who are 75 and older and living alone. Additionally, these seniors have multiple chronic conditions, take six or more medications daily, are functionally impaired, and the single meal provided by the OAA Nutrition Program represents half or more of their total

food intake in a day. Significant numbers live in rural areas, are impoverished and belong to a minority group. In short, the individuals being served are high risk, potentially high cost to Medicare and Medicaid, and are in need of nutrition assistance.

Furthermore, findings from a just-released research study that Meals on Wheels America commissioned Brown University's Center for Gerontology and Healthcare Research to conduct found that those receiving and/or requesting Meals on Wheels services are significantly more vulnerable compared to a nationally representative sample of aging Americans.<sup>1</sup> Specifically, seniors on Meals on Wheels waiting lists were significantly more likely to:

- Report poorer self-rated health (71% vs. 26%)
- Screen positive for depression (28% vs. 14%) and anxiety (31% vs. 16%)
- Report recent falls (27% vs. 10%) and fear of falling that limited their ability to stay active (79% vs. 42%)
- Require assistance with shopping for groceries (87% vs. 23%) and preparing food (69% vs. 20%)
- Have health and/or safety hazards both inside and outside the home (i.e., higher rates of tripping hazards, 24% vs. 10%, and home construction hazards, 13% vs. 7%)

Despite the Meals on Wheels network's successes in effectively targeting our most vulnerable seniors, securing additional public and private resources, and leveraging two million volunteers nationwide, the bedrock federal funding is failing to keep pace with inflation, much less the growth in the senior population or the escalating need. According to *The State of Senior Hunger in America 2013: An Annual Report*, 9.6 million seniors (60+)—or nearly one in six—faced the threat of hunger. Since the start of the recession in 2007, the number of seniors experiencing the threat of hunger has increased by 56%. In 2012, the latest year for which we

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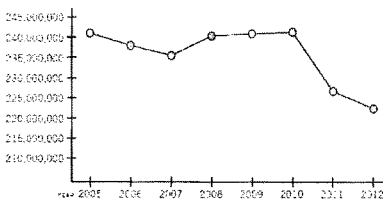
<sup>1</sup> National Health and Aging Trends Study (NHATS), 2014

have data from the Administration on Aging, OAA funding supported the provision of meals to fewer than 2.5 million seniors. Year after year, the gap between those struggling with hunger and those receiving nutritious meals through the OAA continues to widen and waiting lists are mounting nationwide. Members of our organization responding to a recent survey indicated an average waiting list of 135 people per program.

The graphs below, even prior to the 2013 cuts imposed by sequestration, illustrate this troubling trending decline.

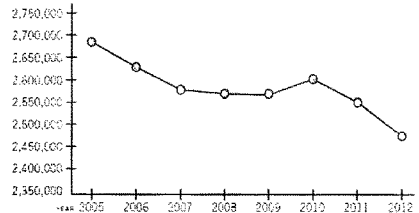
**TOTAL MEALS SERVED BY OAA NUTRITION PROGRAMS**

The number of meals served by the Older Americans Act is declining.



**TOTAL SENIORS SERVED BY OAA NUTRITION PROGRAMS**

The number of seniors served by the Older Americans Act is declining.



Source: Older Americans Act (OAA) Title III Programs data derived from the AGing Integrated Database (AGID) system, the AGID State Profiles. Full reports available at: [www.agingnet.acl.gov](http://www.agingnet.acl.gov)

Even beyond the real people and lives that OAA Nutrition Programs impact on a daily basis, there is increasing and irrefutable evidence that improving and bolstering funding for them will substantially reduce healthcare costs—both in the short- and long-term. On average, a program can deliver Meals on Wheels to a senior for an entire year for the same cost as just one day in the hospital or one week in a nursing home—costs that are often incurred by Medicare and Medicaid.

The recently released *More Than a Meal* study found that those who received daily-delivered meals (the traditional Meals on Wheels model of a daily, in-home-delivered meal, friendly visit and safety check), experienced the greatest improvements in health and quality of

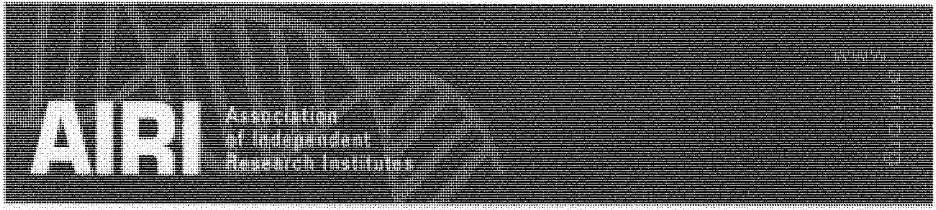
life indicators over the study period, compared to the other two groups (individuals who received frozen, weekly-delivered meals and those who were in the control group on waiting lists).

Specifically, between baseline and follow-up, seniors receiving daily-delivered meals were more likely to exhibit:

- Improvement in mental health (i.e., levels of anxiety)
- Improvement in self-rated health
- Reductions in the rate of falls
- Improvement in feelings of isolation and loneliness
- Decreases in worry about being able to remain in home

We certainly understand the difficult decisions you and your colleagues are tasked with in FY 2016 and beyond. However, the evidence demonstrates that these programs are not only saving lives and taxpayer dollars every day, but they are effectively reaching our nation's most at-risk seniors and have the capacity to serve significantly more, if properly resourced. As such, we ask that you provide the funding levels included in the President's FY 2016 Budget for all three nutrition programs authorized under the OAA—Congregate Nutrition Program, Home-Delivered Nutrition Program, and the Nutrition Services Incentive Program—as well as support the need for Nutrition Innovation Demonstration funding in the FY 2016 Labor-HHS-Education Appropriations Bill. You have the ability to shorten—or even eliminate waiting lists—and increase the number of nutritious meals we can serve to seniors today. At the same time, you will be investing in a stronger fiscal path for our country by reducing future healthcare costs.

Again, thank you for the opportunity to present this testimony to you, and for your continued support. We are also pleased to offer our assistance and expertise at any time throughout this process.



**Written Testimony for the Record Submitted by  
Association of Independent Research Institutes  
for the  
Subcommittee on Labor, Health and Human Services, Education and Related  
Agencies  
Committee on Appropriations, United States House of Representatives**

**Fiscal Year 2016 Funding for the  
National Institutes of Health, Department of Health and Human Services**

**April 29, 2015**

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to continue to improve our nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. **AIRI urges the Subcommittee to provide at least \$32 billion for NIH in fiscal year (FY) 2016.**

The final FY 2015 omnibus appropriations bill included a welcome and much needed increase for NIH. However, this increase did not make up for funds cut by sequestration in FY 2013 nor did it restore the purchasing power NIH has lost over the past decade. In fact, despite budget increases in the each of the past two fiscal years, the NIH budget remains lower than it was in FY 2012 in actual dollars, and since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation.

While the President's FY 2016 budget request for NIH would provide a much needed next step by increasing NIH funding above biomedical inflation, AIRI believes that the ongoing and emerging health challenges confronting the United States and the world, and the unparalleled scientific opportunities to address these burdens demand a funding level of at least \$32 billion in FY 2016. AIRI also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about ten percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is a unique and highly-productive relationship, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the

underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every state.

The federal government has an irreplaceable role in supporting medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems



and applying that knowledge to improve human health and reduce the burdens of illness and disability.

AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall. In addition to concerns over funding, AIRI member institutes oppose legislative provisions – such as directives to reduce the salary limit for extramural researchers – which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such prescriptive policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI members are located in 25 states, including many smaller or less-populated states that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health. However, one of the most destructive and long-lasting impacts of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce.

In addition, strong support for NIH is critical to the nation's competitiveness. This country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and the cuts of sequestration, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the nation, and we appreciate this opportunity to urge the Subcommittee to **provide at least \$32 billion for NIH in the FY 2016 appropriations bill.**



*Empowering people with disabilities to live independently*

**Testimony for the record of  
Sandra Breitengross Bitter, Project Analyst  
Texas State Independent Living Council  
Before the House Committee on Appropriations Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies**

Thank you for taking the opportunity to hear the testimony of the Texas State Independent Living Council about the potential impact of \$200 million in increased funding for Administration on Community Living's Independent Living programs. As you know, with the recent passage of the Workforce Innovation and Opportunity Act, new requirements and opportunities have been presented to the Independent Living network. The addition of new transition-related services for youth transitioning to post-secondary life and for people with disabilities living in institutions or nursing homes or are at risk for entering such a facility, have presented Centers with additional responsibilities to serve their communities.

Centers for Independent Living in Texas do an enormous amount of work to maximize the use of federal, state, and private funding to ensure people with disabilities have the resources they need to live more independently within their own communities. In fact from FY12-FY14, Texas CILs served over 29,000 consumers, have provided nearly 700,000 services, and participated in over 300,000 hours of community activities. We applaud these monumental achievements and we know that they can reach new heights of service if provided additional resources. With the increased level of responsibilities placed on Centers to perform additional services for the community, in addition the many they already provide, we sincerely hope additional federal resources will be available to help them serve these new populations.

Thank you again for this opportunity. We look forward to working with you to ensure people with disabilities have the resources they need to live as independently, with as much choice, as possible.

**Person Submitting Testimony:** Mark Stroh, Executive Director, Disability Rights Washington, 315 5<sup>th</sup> Avenue South, Suite 850, Seattle, WA 98104, 206-324-1521, [mstroh@dr-wa.org](mailto:mstroh@dr-wa.org)

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

Today, I am submitting testimony on behalf of Disability Rights Washington. We are the protection and advocacy system for Washington state. I write today to document, in part, the difference we are making for Washingtonians with intellectual and/or developmental disabilities. We work to assure that laws enacted by Congress and orders issued by courts are implemented as intended. This includes but is not limited to the Olmstead decision ruled on by the U.S. Supreme Court and its mandate related to community integration. It also includes ensuring access to services for people with intellectual and developmental disabilities.

Since President Gerald Ford first signed the Developmental Disabilities and Bill of Rights Act in 1975, Disability Rights Washington, the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program, has been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, Disability Rights Washington monitored conditions and services at 40 different facilities which serve 8,018 individuals and did so 55 occasions. Since we have only four state operated institutions in our Washington, the vast majority of monitoring took place in community settings. We provided information and referral services to 4,977; technical assistance to 1,606 and engaged in five enforcement activities benefitting approximately 14,201 Washingtonians with intellectual and/or developmental disabilities. 11,200 individuals benefitted from a healthier, safer or otherwise improved environment as a result of DRW advocacy.

Here is one example of DRW work with the federal government to assure compliance with Medicaid law which is illustrative of our work.

In 2014, the federal Centers for Medicare and Medicaid Services (CMS) issued a letter which details findings of over 40,000 legal violations with respect to 27 people with developmental disabilities at Lakeland Village over the last two and a half years.

These violations relate to the state's decision to cut services to the individuals who all lived at Lakeland Village, a large state-run institution outside of Medical Lake, WA, 20 miles east of Spokane. Prior to the cuts, the individuals were receiving numerous services daily to help them develop and maintain their skills, such as employment support, physical therapy, speech therapy, and support in gaining hygiene and interpersonal relationship skills.

In response to a directive to cut \$1,887,700 in 2011, the Department of Social and Health Services' (DSHS) Developmental Disabilities Administration (DDA) decided to save money by withholding these treatments for these 27 residents. The state's choice to save money on the backs of these 27 people was a choice to give up on each of these individuals. They saved money only because they stopped providing necessary daily services that these residents, until that point, received to develop greater abilities and quality of life.

The state has a long history of such cost saving efforts and many more people at Lakeland and other state-run facilities are in similar situations.

Disability Rights Washington (DRW) met with DDA to let them know how illegal these actions were even before the 2011 cuts were made, but the state went ahead with them anyway. DRW then initiated an intensive investigation involving the review of thousands of pages of client records. DRW sent a letter to DDA detailing its findings along with legal support and over one hundred pages of client records illustrating the specific violations and harm caused by the state's cost saving scheme. Over a year later, residents were still being denied those services. CMS, the federal agency which oversees the money spent on facilities such as Lakeland Village, identified the same issues and initiated its own investigation.

Since the state is not allowed to take federal money to pay for services that do not meet the basic minimum standards established by the federal government, CMS demanded the state pay back the

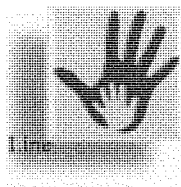
federal money the state inappropriately spent on these individuals during this time and is requiring the state take immediate action to deliver the necessary services each resident requires.

Beyond requiring reimbursement of federal funds and a plan of correction, CMS referred the matter to the federal Department of Health and Human Services Office of Civil Rights which is charged with investigating, negotiating, and litigating violations of civil rights by recipients of federal Medicare and Medicaid funds.

At the time the federal agency also indicated that this was just the first in what will be several letters about the state's compliance with the same legal requirement to provide adequate treatment to people with developmental disabilities living in other units at Lakeland Village and at other state-run institutions in central and western Washington.

Thank you for this opportunity to submit this testimony.





Children's  
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April 28, 2015

**Testimony submitted by Cynthia Bearer, M.D., Ph.D., M.P.H. on behalf of the Children's  
Environmental Health Network before the Subcommittee on Interior, Environment, &  
Related Agencies  
United States House Committee on Appropriations**

Regarding U.S. Environmental Protection Agency (EPA) and the Agency for Toxic Substances and Disease Registry (ATSDR) FY2016 Appropriations

The Children's Environmental Health Network (CEHN or the Network) is pleased to submit testimony on FY 2016 appropriations for the U.S. Environmental Protection Agency (EPA) and the Agency for Toxic Substances and Disease Registry (ATSDR). We seek funding levels of \$9 billion for EPA and \$76.2 million for ATSDR. CEHN urges the Subcommittee to provide funding at or above the requested levels for the following EPA activities: Office of Children's Health Protection; Children's Environmental Health & Disease Prevention Research Centers; Office of Research & Development; School and Child Care Environmental Health; and the Pediatric Environmental Health Specialty Units. CEHN also urges the restoration of the State Indoor Radon Grants and full funding of all activities that advance healthy school and childcare environments for all children, including those supported by ATSDR.

The Network's mission is to protect the developing child from environmental hazards and promote a healthier environment; the Board and committee members include internationally-respected experts in children's environmental health science and policy. We recognize that children, in our society, have unique moral standing. Today's children are facing the distressing

possibility that they may be the first generation to see a shorter life expectancy than their parents due to poor health. Key contributors to this trend are obesity, asthma, learning disabilities, and autism. For all of these conditions, the child's environment plays a role in causing, contributing to or mitigating these chronic conditions. The estimated costs of environmental disease in children (such as lead poisoning, childhood cancer, and asthma) were \$76.6 billion in 2008.<sup>1</sup> Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures. Further, a growing number of studies are finding unexpected impacts of prenatal environmental exposures on health in later years. For example, prenatal exposures to either a common air pollutant or a common pesticide have each been linked to lower IQs and poorer working memory at age 7. All agencies should assure that their children's programs build on and respond to the growing evidence of the importance of prenatal and early life exposures to a child's health and future.

**Environmental Protection Agency:** A variety of factors, such as children's developing systems, their unique behaviors, and differing exposures, mean that children can be more susceptible than adults to harm from toxic chemicals. Standards and guidelines that are based on adults cannot be assumed to be protective of children. The EPA programs of highest importance in the protection of children are described below.

**EPA's Office of Children's Health Protection (OCHP)** – OCHP has been leading EPA's efforts to protect children from environmental hazards since 1997. Despite an effective track record, funding for OCHP has been level, at approximately \$6 million, since its creation. OCHP focuses on interagency work that promotes healthy housing and healthy children. These areas

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<sup>1</sup> Trasande, Liu Y. "Reducing The Staggering Costs Of Environmental Disease In Children, Estimated At \$76.6 Billion In 2008," *Health Affairs*. No. (2011): doi: 10.1377/hlthaff.2010.1239

show that environmental interventions result in great cost savings, not to mention the health problems averted, such as asthma episodes and lead poisoning cases. We urge increased funding for this vital office.

**Children's Environmental Health & Disease Prevention Research Centers** – These Centers, jointly funded by EPA and NIEHS, play a key role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, which have been unchanged for more than 10 years, these centers generate valuable research. These centers, for example, generated the findings mentioned earlier about connections between prenatal exposures and lower IQ at age 7; several Centers have established longitudinal cohorts, which in some cases are more than 10 years old. Few if any longitudinal cohort studies on adolescents, puberty and environmental exposures exist. We urge the Subcommittee to support these centers at \$33 million in FY 2016.

**Office of Research & Development (ORD)** – This office is critical in efforts to understand environmental impacts on children's health. EPA has pledged to increase its efforts to provide a safe and healthy environment for children by ensuring that all EPA regulations, standards, policies, and risk assessments take into account childhood vulnerabilities to environmental chemicals. We ask that your subcommittee direct the office to improve transparency by tracking and reporting on the funding and research across the office dedicated to children's environmental health. Children's environmental health is an issue that cuts across all of ORD's programs. For example, EPA's National Health and Environmental Effects Research Laboratory scientists are protecting children's health through the development of cost-effective methods to test and rank

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chemicals for their potential to cause developmental neurotoxicity. To date, only a small number of the thousands of chemicals currently in commerce have been assessed for their potential toxicity and for their effects on the child's developing nervous system. These new testing methods can screen in hours to days instead of months to years and will provide faster, less expensive ways of assessing potential toxicity. There is continued need for research in childhood exposures and health effects. Much of the research in this field cannot be conducted in a short time frame and requires sustained funding if scientists are to conduct research and measure effectiveness.

**State Radon Grants:** Radon is the leading cause of lung cancer in non-smokers, and the EPA reports that it is one of the most serious public health problems in the U.S., responsible for up to 21,000 lung cancer deaths annually. While we applaud the Agency's continued work on indoor air quality, asthma, and its plans to "continue to lead on radon activities," we are not convinced that the way to do so is to eliminate the state Indoor Radon Grants. We urge you to restore this program.

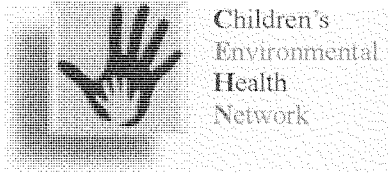
**School and Child Care Environmental Health** – In America today, millions of children, often as young as 6 weeks, spend 40-50 hours a week in childcare. Yet, little is known about the environmental health status of the nation's childcare centers or how to assure that these facilities are protecting this highly vulnerable group of children. Environmental health is rarely if ever considered in licensing regulations or in training childcare professionals. Similarly, about 54 million children and nearly 7 million adults —20% of the total U.S. population—spend up to 40 hours per week inside school facilities every week. Unfortunately, many of these facilities contain unsafe environmental conditions that harm children's health and undermine attendance,

achievement, and productivity. Thus, it is vital that EPA maintain and expand its activities for healthy school and child care settings, such as the Indoor Air Quality Tools for Schools program.

**Pediatric Environmental Health Specialty Units** -- Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network for parents and clinicians around the nation. They are funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA with a very modest budget. PEHSU professionals provide medical consultation to health care professionals from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. We urge the Subcommittee to provide adequate funding for both EPA's and ATSDR's portions of this program.

**ATSDR:** CEHN urges the Subcommittee to provide funding at or above the requested levels for ATSDR activities. ATSDR uses the best science in taking public health actions, such as site assessments and toxicological profiles, to prevent harmful exposures and diseases of communities and individuals related to toxic substances. ATSDR understands that in communities faced with contamination of their water, soil, air, or food, infants and children can be more sensitive to environmental exposure than adults and that assessment, prevention, and efforts to find remedies for exposures must focus on children because of their vulnerability and importance to the nation's future. We support the full funding of ATSDR and the continuation of their varied responsibilities.

Thank you for the opportunity to submit testimony on these critical issues.



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April 28, 2015

**Testimony submitted by Cynthia Bearer, M.D., Ph.D., M.P.H. on behalf of the Children's Environmental Health Network before the Subcommittee on Labor, Health & Human Services, Education & Related Agencies  
United States House Committee on Appropriations**

Regarding FY2016 Appropriations for children's environmental health programs

The Children's Environmental Health Network (CEHN or the Network) is pleased to have this opportunity to submit testimony on FY 2016 appropriations for the following programs and activities that safeguard the health and future of all of our children:

- Centers for Disease Control and Prevention (\$7.8 billion), especially the National Center for Environmental Health (\$212.46 million) and its programs, including:
  - Healthy Homes and Lead Poisoning Prevention Program (\$29 million)
  - National Asthma Control Program (\$28 million)
  - National Environmental Public Health Tracking Program (\$40 million)
- National Institute of Environmental Health Sciences (NIEHS) (\$717.7 million), especially the Children's Environmental Health Research Centers (\$33 million)
- Pediatric Environmental Health Specialty Units (PEHSUs) (\$2 million)

The Children's Environmental Health Network (CEHN) was created more than 20 years ago by concerned pediatricians and researchers with a goal of protecting the developing child from environmental health hazards and to promote a healthy environment. Today's children are facing the distressing possibility that they may be the first generation to see a shorter life expectancy

than their parents due to poor health. Key contributors to this trend are obesity, asthma, learning disabilities, and autism. For all of these conditions, the child's environment plays a role in causing, contributing to or mitigating these chronic conditions. The estimated costs of environmental disease in children (such as lead poisoning, childhood cancer, and asthma) were \$76.6 billion in 2008.<sup>1</sup> Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures.

Additionally, protecting our children -- those born as well as those yet to be born -- from environmental hazards is a national security issue. When we protect children from harmful chemicals in their environment, we help to assure that they will reach their full potential. American competitiveness depends on having healthy, educated children who grow up to be healthy productive adults. It is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. We strongly urge the Committee to support and expand children's environmental health programs. Key programs in your jurisdiction deserving your support include:

#### **Centers for Disease Control and Prevention (CDC)**

As the nation's leader in public health promotion and disease prevention, the CDC should receive top priority in federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of \$7.8 billion for CDC's core programs in FY 2016.

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<sup>1</sup> Trasande, Liu Y. "Reducing The Staggering Costs Of Environmental Disease In Children, Estimated At \$76.6 Billion In 2008, *Health Affairs*. No. (2011): doi: 10.1377/hlthaff.2010.1239

*Children's Environmental Health Network*  
Testimony for the record on FY2016 Labor/HHS appropriations  
Page 3

The **National Center for Environmental Health (NCEH)** is particularly important in protecting the environmental health of young children. Current research is uncovering the extensive role that environment plays in human health and development. As a result, NCEH partners with public health agencies and a wide range of other organizations to bring their expertise and support to an expanding scope of environmental-human health challenges. NCEH's programs are key national assets. Yet in recent years, NCEH funding has been drastically cut. We urge the Subcommittee to at least restore NCEH to its FY2010 funding level of \$212.46 million.

We were deeply concerned with the FY 2012 gutting of the **Healthy Homes and Lead Poisoning Prevention Program** and we commend you for the substantial increase the program received in FY2014. This program helps to prevent lead poisoning and helps children who have already been exposed to lead. Much more needs to be done just to return it to FY 2011 levels. Millions of American children remain at risk of lead poisoning and need this program, which supports effective local and state efforts. As evidence increasingly demonstrates no safe level of lead exposure for children, this funding is all the more essential. We urge a funding level of \$29 million in FY 2016.

NCEH's **National Asthma Control Program** not only has greatly increased data collection about this rampant epidemic but it also encourages states to use evidence-based approaches to reduce costs and improve outcomes for people living with asthma. Asthma is an epidemic in the U.S., affecting 10% of our nation's children. We urge the Committee to fund this vital program at \$28 million in FY 2016.



Public health officials need integrated health and environmental data so that they can protect the public's health.

The CDC's **National Environmental Public Health Tracking Program** helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, state and Federal health agencies' collection of critical health and environmental data. Participation in the tracking network development will decline under further cuts and erase the progress we have made across the country to better link data with public health action.

#### **National Institute of Environmental Health Science (NIEHS)**

**NIEHS** is the leading institute conducting research to understand how the environment influences human health. Unlike other NIH Institutes focused on one disease or one body system, NIEHS is charged with all diseases, all human health and body systems, as they are affected by the environment – a vital and monumental charge. NIEHS plays a critical role in our efforts to understand how to protect children, whether it is identifying and understanding the immediate impact of chemical substances or understanding childhood exposures that may not affect health until decades later. CEHN recommends that \$717.7 million be provided for NIEHS' FY 2016 budget.

#### **Children's Environmental Health Research Centers of Excellence**

The Children's Environmental Health & Disease Prevention Research Centers, jointly funded by the NIEHS and the U.S. Environmental Protection Agency (EPA) and located at research institutions across the nation, play a vital role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, these centers are generating invaluable research. For example, these centers conducted the recent research that found links

between prenatal exposures to either a common air pollutant or a common pesticide to lower IQs and poorer working memory at age 7.

Several Centers have established longitudinal cohorts, which in some cases are more than 10 years old. The ability to look for linkages between exposures and health outcomes in infants, toddlers, and, now, adolescents, is vital. If these cohorts are disbanded due to funding cuts, at best it will take years and untold resources before it is possible to replicate them. Few if any longitudinal cohort studies on adolescents, puberty and environmental exposures exist. The Network is concerned that inadequate funding may result in the loss of these valuable cohorts. We urge the Subcommittee to support these centers at \$33 million in FY 2016.

#### **Pediatric Environmental Health Specialty Units**

Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network for parents and clinicians around the nation. They are funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA with a very modest budget. PEHSU professionals provide medical consultation to health care professionals from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. We urge the Subcommittee to fully fund ATSDR's portion of this program in FY 2016.

In conclusion, our nation's future will depend upon its future leaders. Protecting children from harmful chemicals in their environment will result in healthier children with brighter futures, an outcome we can all support. Thank you for the opportunity to testify.

**PATH Outside Written Testimony for the Record**  
**Heather Ignatius, Senior Policy and Advocacy Officer, PATH**  
**April 29, 2015**

PATH is appreciative of the opportunity afforded by Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, to submit written testimony regarding fiscal year (FY) 2016 funding for global health and immunization initiatives at the US Department of Health and Human Services (HHS). We appreciate the strong leadership this Committee has shown in supporting global health and immunization programs and we ask that your support continue. I am submitting this testimony on behalf of PATH, an international nonprofit organization that drives transformative innovation to save lives and improve health in developing countries, especially among women and children. For nearly 40 years, PATH has been a pioneer in translating bold ideas into breakthrough health solutions. We accelerate innovation across five platforms—vaccines, drugs, diagnostics, devices, and systems and service innovations. We actively collaborate with public- and private-sector partners—including the US government and HHS—to develop new and adapt existing innovations across the health spectrum, and to work to ensure those solutions reach the people who need them the most, in the lowest resource settings. Through our work in more than 70 countries, we see firsthand the impact of US government investments in global health and immunization. **We respectfully request that this Subcommittee ensure robust funding for HHS global health programs in FY 2016 to allow the US government to achieve goals outlined in the US National Vaccine Plan and the new six-year President's Malaria Initiative Strategy.**

**The vital role of HHS in global health**

The ongoing Ebola crisis and the measles outbreaks in California and New York in early 2015, have demonstrated that the health of US citizens is inherently connected to the health of people living around the globe. Global pandemics and increasing overseas travel in recent decades intensify Americans vulnerability to infectious diseases that have historically impacted communities outside our borders.

Recognizing this, HHS has been active in global health programs for decades. In recent years, HHS developed the Global Health Strategy (2011) and serves as the lead US agency for the Global Health Security Agenda (launched in 2014) to better protect Americans' health and security while improving health around the world.

### **Accelerating progress toward global immunization goals**

A key strategy for achieving HHS' global health goals is immunization. Vaccines are one of the most impactful and cost-effective public health interventions available today. They have played a large role in cutting the number of deaths of children under age five in half since 1990. Worldwide, polio cases have dropped by more than 99 percent since 1988, measles deaths have declined by 75 percent from 2000 through 2013, and 2 to 3 million deaths are averted each year through immunization. HHS has contributed significantly to this achievement. For example, thanks in part to HHS' role in global polio immunization efforts, including as a leading agency in the Global Polio Eradication Initiative, 11.5 million children were reached with polio vaccine in 2014. Southeast Asia, including India, was certified polio-free in March 2014, making 80 percent of the world's population polio-free. Only three countries—Afghanistan, Pakistan, and Nigeria—remain "endemic," meaning they have never interrupted transmission of the virus, but promisingly, Nigeria has not reported a case of wild polio since July 2014.

Robust funding will enable HHS to further extend the reach of lifesaving vaccines to where they are needed most, which will save even more lives and contribute to healthier, more productive communities.

Global immunization is one of five core objectives of the US National Vaccine Plan (2010-2015), emphasizing its role in providing an "umbrella of protection" for the United States. This year is a pivotal moment as HHS agencies work to update this plan and outline priorities for the next five years. In parallel to this plan, the CDC is in the process of developing a revised global immunization strategy. Full funding is essential to ensure they can effectively execute these strategies and support the dual objectives of protecting the health of Americans while improving children's lives overseas.

2015 marks the halfway point of the Decade of Vaccines, an initiative which established a global framework endorsed by the United States and 193 other nations with the aim of delivering universal access to immunization. While some progress has been made toward the goals outlined in the framework, and individual achievements in countries have demonstrated what is possible with focused efforts, we are off track to meet many of the milestones outlined in the plan, and the delay means more lives lost. The US government is positioned to lead the way in accelerating progress toward the framework's goals, if it maximizes its contributions across various agencies. We are pleased to see HHS making strides toward strengthening the collective impact of its agencies engaged on global immunization, including the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Food and Drug Administration (FDA), among others, as well as across other departments of the US government. We urge the committee to continue to fully fund these efforts and encourage stronger coordination.

**Supporting vaccine introduction and scale**

CDC and other partner agencies play a key role in ensuring that appropriate vaccines are introduced and widely available where they are needed most. When new and improved vaccines become available, countries must weigh several factors when deciding whether or not, and how, to introduce the vaccine. CDC provides valuable epidemiological, laboratory, and policy expertise to help build the capacity of countries to make informed decisions and plan for incorporating new vaccines into their immunization program.

**Strengthening global immunization systems**

Effectively delivering immunizations requires coordination at every level of the immunization system. CDC partners with domestic health ministries and the World Health Organization to ensure that health systems are robust and able to operate effective immunization programs, including human resources, processes, tools, and equipment.

Investments in immunization infrastructure have proven invaluable in promoting health more broadly and rapidly responding to outbreaks. For example, Nigeria was able to rapidly adapt its polio infrastructure, built with significant CDC input and support, to respond to an importation of Ebola in October 2014 in Lagos. Senior polio leadership quickly established an Emergency Operations Center in Lagos to respond to the outbreak, stopping the virus without incident. Meanwhile, immunization rounds in northern Nigeria continued as planned without a decrease in quality. This effort demonstrated the quality and resilience of the program in Nigeria, and the adaptability of polio assets for use in other public health issues.

### **Fighting to eliminate malaria**

In addition to its critical work in immunization, HHS has a long history in the fight to eliminate malaria. CDC, in particular, played a critical role in eliminating malaria from the United States. As a joint implementer of the President's Malaria Initiative (PMI) alongside the US Agency for International Development (USAID), the CDC continues to play a leading role in global elimination efforts. Between 2001 and 2013, an estimated 4.2 million lives were saved as a result of scaled up malaria interventions. Recently PMI set forth a new six-year strategy which includes an ambitious agenda to reduce malaria mortality by one-third from 2015 levels in PMI-supported countries, thereby achieving a greater than 80 percent reduction from PMI's original 2000 baseline. Robust funding is required to execute on this goal.

With evidence of growing insecticide and drug resistance, CDC's role in malaria surveillance and ensuring we have the tools necessary to fight this ever changing disease is critical. CDC provides the routine surveillance that is critical in keeping up with the changing dynamics of the disease, provides scientific leadership and training to the next generation of malaria technical experts, and works to develop and evaluate new tools to aid in the fight. Examples of CDC's contributions include evaluations of the impact of improved nets, insecticides, and strategic use of antimalarial drugs, as well as field trials of promising malaria vaccine candidates.

However as CDC's mandate has grown, their budget for malaria has been flat funded. Increased funding would better equip the agency to track the spread of drug and insecticide resistance, develop and deploy new tools, and ensure the more timely surveillance that is necessary for ultimate malaria elimination.

### **Protecting US leadership in global health R&D**

While access to existing, proven health interventions—whether vaccines, bednets, or drugs—must be extended, it is also critical to support research and development (R&D) into future technologies that can prevent existing and emerging global health threats. Investments made by the US government, including through the NIH and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have improved health and saved lives around the world. These innovations include new and improved vaccines, such as an effective, low-cost vaccine against meningitis A, which used to cause devastating outbreaks each year in Africa's Meningitis Belt. Zero cases of meningitis A have occurred among the more than 215 million Africans vaccinated since 2010. Thanks to a discovery made by scientists at NIH, PATH was able to develop a simple, rapid test for exposure to river blindness, a disease that affects 23 million people. This test was launched commercially last year and is an important tool in the fight to eliminate river blindness in Africa. The promise of new global health technologies can only be realized when products are developed, tested, and scaled up for use globally. Strengthened collaboration and coordination between HHS operating divisions and other US agencies funding vaccine development and delivery will be critically important to align priorities and maximize investments.

### **An investment in health, at home, and around the world**

With strong funding for HHS, the department will be able to improve access to existing, proven health interventions in the communities where they are needed most. By fully funding the global health and immunization-related accounts, the US can protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy lives and reach their full potential.

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**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES**

**FOR FISCAL YEAR 2016  
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS**

SUMMARY OF FY16 RECOMMENDATIONS

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF \$1 BILLION OVER FY 2015. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**
- 2) SUPPORT THE NIH PORTFOLIO ON VIRAL HEPATITIS AND OTHER LIVER DISEASES AND LIVER CANCERS WITHIN NIDDK'S LIVER DISEASE RESEARCH BRANCH.**
- 3) \$62.82 MILLION FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S (CDC) DIVISION OF VIRAL HEPATITIS.**

Thank you for the opportunity to submit testimony on behalf of the American Liver Foundation. Founded in 1976, the American Liver Foundation (ALF) is the nation's leading nonprofit health organization for people living with liver disease. ALF is a nationwide network of staff and volunteers that provides awareness, outreach, education and patient support services to educate the public about liver health and to improve the lives of individuals and their families affected by liver disease.

ALF's mission is to facilitate, advocate and promote education, support and research for the prevention, treatment and cure of liver disease, including focusing on hepatitis C, which untreated leads to liver disease.

ALF makes measurable difference in the fight against liver disease by providing resources for medical research, educating patients, families, caregivers, and healthcare professionals, advocating for patients and their families, and creating public awareness campaigns about liver wellness and disease prevention.



My own story with liver disease dates back to the summer of 1983, when I was born a premature baby and spent the next several months in the Neonatal Intensive Care Unit (NICU). It was there that I received multiple blood transfusions that were the likely source for my acquisition of Hepatitis C. I lived the next 26 years without knowing of my diagnosis, until an incidental needle-stick during my medical residency training ultimately led to my understanding of my own liver disease. As a physician who became a patient in an instant, I was scared of both what I knew about Hepatitis C and more importantly, of what I didn't know what would happen with me and my future. From the summer of 2010 to the early winter of 2011, I underwent treatment with interferon and ribavirin. Despite a myriad of side effects including flu-like feelings for days and feelings of depression, I was able to get through the treatment and learn six months later that I had been cured of my Hepatitis C.

## **FACTS**

The liver is one of the body's largest organs, performing hundreds of functions daily including, removal of harmful substances from the blood, digestion of fat, and storing of energy. Non-alcoholic fatty liver disease (NAFLD), hepatitis C, and heavy alcohol consumption are the most common causes of chronic liver disease or cirrhosis (severe liver damage) in the U.S. Approximately 30% of adults and 3-10% of children have excessive fat in the liver or NAFLD which can lead to a severe liver disease called non-alcoholic steatohepatitis (NASH). Approximately 4.4 million Americans are living with Hepatitis B or C but most do not know they are infected. More than 2 million Americans are living with alcohol related liver disease. Approximately 5.5 million Americans are living with chronic liver disease or cirrhosis. Vaccinations for hepatitis A and B and treatments for hepatitis C are helping to change the course of this chronic life altering disease for the patient community.

ALF would like to thank the Subcommittee for its past support of liver disease and viral hepatitis research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically ALF recommends:

- 32 billion for the NIH
- \$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) with support for the Liver Diseases Research Branch
- \$62.82 million for CDC's Division of Viral Hepatitis

We at the ALF respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the ALF would like to highlight the current advancements being made.

## **VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH**

ALF applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. ALF urges that funding be focused on expanding the capability of state health departments, particularly to enhance resources available to the hepatitis state

coordinators. ALF also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

ALF supports \$62.82 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. ALF also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

### **DIGESTIVE DISEASE COMMISSION**

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

ALF recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address liver diseases, cancers, and the epidemic of Viral Hepatitis.

### **CONCLUSION**

As I look back at my own experience with liver disease and Hepatitis C, I know I was lucky. I was fortunate to get needle stuck and learn of my diagnosis. I was fortunate to live in a time that had great drugs that have changed the game of treating this liver disease. And I was fortunate to have access to these treatments that allowed me to say I too am cured.

ALF understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on liver disease research conducted through the National Institutes of Health. On behalf of the millions of liver disease and viral hepatitis patients, we appreciate your consideration of the views of the American Liver Foundation. We look forward to working with you and your staff.

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**SUBMITTED TO:  
SUBCOMMITTEE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES  
COMMITTEE ON APPROPRIATIONS  
UNITED STATES HOUSE OF REPRESENTATIVES**

**REGARDING FISCAL YEAR 2016 APPROPRIATIONS FOR  
DEPARTMENT OF HEALTH AND HUMAN SERVICES: NATIONAL INSTITUTES OF  
HEALTH—NATIONAL HEART, LUNG, AND BLOOD INSTITUTE, AND THE  
CENTERS FOR DISEASE CONTROL AND PREVENTION**

As you begin to craft the Fiscal Year 2016 (FY16) Labor-HHS-Education appropriations bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide \$32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), \$1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), full support for the National Center on Sleep Disorders Research (NCSDR), and implementation of the 2011 *NIH Sleep Disorders Research Plan*. These actions will ensure increased awareness of the importance of sleep and circadian rhythms and further the advancements being made by sleep researchers to better understand the relationship between sleep and health.

#### **SLEEP RESEARCH SOCIETY**

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,100 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50-70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20% of motor vehicle injuries. The widespread effect of sleep disorders on every age group poses a public health risk, extending from the ability to learn to maintain a healthy lifestyle. Furthermore, it is important to recognize that sleep disorders and circadian disturbances are often an indicator of, or a precursor to other major diseases and disorders including: obesity, diabetes, hypertension, cardiovascular disease, stroke, depression, bipolar disorder, and substance abuse. Another increasingly detrimental

condition affecting 15% of the population is sleep-disordered breathing, including obstructive sleep apnea. Sleep apnea results in excessive daytime somnolence, poor performance, increased frequency of road traffic accidents, and arterial hypertension. Studies show that 85% of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51%). If left untreated, obstructive sleep apnea has significant negative impacts on health, including early mortality.

### **NATIONAL INSTITUTES OF HEALTH**

Due to the fact that sleep is a multi-disciplinary issue, many institutes and centers at NIH, utilize a portion of their funding to support sleep and circadian research. The majority of sleep research is coordinated by NHLBI, particularly the National Center on Sleep Disorders Research. An appropriation of \$32 billion for NIH, and \$3 billion for NHLBI, is needed to facilitate the continued growth and advancement in the sleep and circadian research portfolio.

The reason NCSDR is housed at NHLBI is due to the important link between sleep disorders and cardiovascular health. NCSDR supports research, health education, and research training related to sleep-disordered breathing and the fundamental function of sleep and circadian rhythms. Furthermore, NCSDR coordinates sleep research across NIH and with other federal agencies and outside organizations.

NCSDR's coordinating role between institutes is made possible through adequate funding. These research activities also have far reaching effects, beginning with training grants targeted towards undergraduate students and career development opportunities attracting top talent in doctoral programs. Sequestration has the potential to disrupt the research training pipeline by reducing the amount of K, T, and F series awards for new investigators. It could also disrupt the career development pipeline designed to train future investigators who are pursuing research in sleep disorders and circadian rhythms. It is important to fund NIH at \$32 billion and NHLBI at \$3 billion in FY16 so that we can continue these advancements in sleep and circadian research.

### **CENTERS FOR DISEASE CONTROL AND PREVENTION**

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. Most notably, CDC engages in the National Healthy Sleep Awareness Project which conducts research on prevalence and incidence of sleep disorders, and raises awareness on the importance of healthy sleep through the production of state fact sheets, updating the CDC website, and disseminating information on sleep related topics. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at \$7.8 billion including an allocation of \$1 million solely for sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program, so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

### **NIH SLEEP DISORDERS RESEARCH PLAN**

NCSDR published the *NIH Sleep Disorders Research Plan* in November of 2011 highlighting the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep and circadian rhythm disorders. A Joint Task Force between the two leading organizations representing the sleep medicine and research community, Sleep Research Society (SRS) and American Academy of Sleep Medicine (AASM), has identified research opportunities that will have the highest impact on health within the plan.

The Plan recommends implementation of the following sleep research goals which will help us understand the function of sleep and inform individuals on healthier lifestyle choices:

- Advance the understanding of sleep and circadian functions and of basic sleep and circadian mechanisms, in both the brain and the body, across the lifespan.
- Identify genetic, pathophysiological, environmental, cultural, lifestyle factors, and sex and gender differences contributing to the risk of sleep and circadian disorders and disturbances, and their role in the development and pathogenesis of co-morbid diseases and disability.
- Improve prevention, diagnosis, and treatment of sleep and circadian disorders, chronic sleep deficiency, and circadian disruption, and evaluate the resulting impact on human health.
- Enhance the translation and dissemination of sleep and circadian research findings and concepts to improve health care, inform public policy, and increase community awareness to enhance human health.
- Enable sleep and circadian research training to inform science in cross-cutting domains, accelerate the pace of discovery, and the translation of enhanced therapies from bench to bedside to community.

Research activities and stakeholders addressed by the plan benefit from the encompassing range of NIH research, training, and outreach programs. Over the past two years, steps have been taken to implement portions of this research plan, but additional work needs to be done. SRS encourages you to recommend that this research plan continue to be implemented during FY16.

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

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**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES**

**ON THE  
FISCAL YEAR 2016  
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS**

SUMMARY OF FY16 RECOMMENDATIONS

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF \$1 BILLION OVER FY 2015. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**
- 2) CONTINUE FOCUS ON DIGESTIVE DISEASE RESEARCH AND EDUCATION AT NIH, INCLUDING INFLAMMATORY BOWEL DISEASE (IBD), HEPATITIS AND OTHER LIVER DISEASES, IRRITABLE BOWEL SYNDROME (IBS), COLORECTAL CANCER, ENDOSCOPIC RESEARCH, PANCREATIC CANCER, AND CELIAC DISEASE.**
- 3) \$62.82 MILLION FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S (CDC) DIVISION OF VIRAL HEPATITIS.**
- 4) \$50 MILLION FOR THE CENTER FOR DISEASE CONTROL AND PREVENTION'S (CDC) COLORECTAL CANCER SCREENING AND PREVENTION PROGRAM.**

Thank you for the opportunity to submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 50 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted

activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the Subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends:

- 32 billion for the NIH.
- \$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints under which the Subcommittee currently operates, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

### **INFLAMMATORY BOWEL DISEASE**

In the United States today about 1.4 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The DDNC encourages the Subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in FY16.

### **VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH**

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of state health departments, particularly to enhance resources available to the hepatitis state coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports \$62.82 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis

Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

### **COLORECTAL CANCER PREVENTION**

Colorectal cancer is the third most commonly diagnosed cancer for both men and women in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

### **PANCREATIC CANCER**

In 2013, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 1 out of 4 patients will live one year after the cancer is found and only 1 out of 25 will survive five or more years. The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

### **IRRITABLE BOWEL SYNDROME (IBS)**

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge. Patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

### **DIGESTIVE DISEASE COMMISSION**

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can



be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

The DDNC recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address the numerous digestive disorders that remain in today's diverse population.

### **CONCLUSION**

The DDNC understands the challenging budgetary constraints, as well as the times in which we live and under which this Subcommittee is operating. Yet we hope you will carefully consider the tremendous benefits to be gained by supporting a robust research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. On behalf of the millions suffering with digestive diseases, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

## Outside Witness Testimony

From the American Psychological Association (APA)

Re Fiscal Year 2016 Appropriations for

Labor, Health and Human Services and Education

U.S. House Committee on Appropriations

April 29, 2015

The APA is the largest scientific and professional organization representing psychology in the US: its membership includes nearly 130,000 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

**National Institutes of Health** –Sub-inflationary spending increases have eroded NIH’s purchasing power and left many innovative research projects unfunded during the last ten years. APA recommends that NIH receive at least \$32 billion in FY 2016 as the next step toward a multi-year increase in our nation’s investment in health research. Psychological scientists are supported by research grants or training programs in almost all of NIH’s 27 institutes and centers. Behavioral research is critical to NIH’s mission: the Institute of Medicine recently reaffirmed that over 50 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption.

APA is a strong supporter of the OppNet initiative, which has stimulated over \$71.5 million in basic behavioral and social sciences research in 167 projects that might not have otherwise been supported. APA urges the Committee to examine the NIH’s evaluation of the program when it is completed, and to encourage NIH not only to support the now-voluntary program but to seed new collaborative efforts to

support basic behavioral and social science research that may be applied to advance the missions of many of the different NIH institutes.

APA endorses the National Institute of Child Development's continued focus on basic and applied research with human and animal studies to advance our understanding of attachment in mother-infant relationships and its impact on development.

APA also strongly supports the launch of the Adolescent Behavioral and Cognitive Development (ABCD) study under the auspices of NIH's Collaborative Research on Addictions (CRAN) initiative. The ABCD will recruit 10,000 youth before they begin using alcohol, marijuana, nicotine and other drugs, and follow them over 10 years into early adulthood to assess how substance use affects the developing brain.

**Centers for Disease Control and Prevention--** APA supports at least \$7.8 billion for core programs in FY 2016; the President's request for increased funding for the National Injury Prevention and Control Center, including \$25 million for the National Violent Death Reporting System, to allow for its expansion to all 50 states and DC; and \$10 million in research into the causes and prevention of gun violence. APA recommends \$172 million for FY 2016 for the National Center for Health Statistics.

Most new HIV infections in this country are among young people under 25, specifically among Black young men who have sex with men (MSM). APA encourages the Committee to maintain the President's \$6 million increase for the Division of HIV/AIDS Prevention (DHAP) to expand youth HIV prevention efforts in schools and non-school settings.

**Substance Abuse and Mental Health Services Administration**-- APA strongly supports the \$44.6 million increase in funding to support increased initiatives to strengthen crisis systems and address prescription and opioid abuse. Additionally APA supports:

- The National Child Traumatic Stress Network (NCTSN) program. APA recommends increased support for the Network's efforts on behalf of the recovery of children, families, and communities affected by trauma and violence.
- Garrett Lee Smith Memorial Act programs--Campus Suicide Prevention, State and Tribal Youth Suicide Prevention and the Suicide Prevention Resource Center. These effective national programs help meet the mental and behavioral health needs of youth and young adults to reduce suicide risk in these populations.
- Minority Fellowship Program - While minorities represent 30% of the U.S. population and are projected to increase to 40% by 2025, only 23% of recent doctorates in psychology, social work and nursing were awarded to minorities. We ask the Committee to support level funding of the Minority Fellowship Program as requested by the Administration.
- Mental Health Care Provider Education in HIV/AIDS Program in CMHS- APA urges Congress to maintain level funding in CMHS for the training of psychologists, social workers, and psychiatrists for services to people with HIV/AIDS.
- SAMHSA's Safe Schools/Healthy Students program that expands access to mental and behavioral health services in schools and reduces violence through prevention and early intervention.

**Health Resources and Services Administration** -- APA strongly recommends funding services to individuals with perinatal depression. Postpartum depression (PPD) and perinatal depression are

commonly undiagnosed conditions associated with childbirth. In the U.S., approximately one in five women suffers from PPD each year. Under current USPSTF guidelines, depression screening is available as an Essential Health Benefit to all non-pregnant adults, yet excludes the vulnerable population of pregnant women. APA supports funding for PPD research and treatment under Section 512 of the Social Security Act, to incorporate screening and linkages to behavioral health treatment for women suffering from this condition.

APA recommends continued investments in the mental and behavioral health workforce, including \$9.9 million for the Graduate Psychology Education program to increase the number of health service psychologists trained to provide integrated services to high-need underserved populations. This program supports the training of doctoral psychology students, interns and postdoctoral residents with other health professionals while they provide supervised mental and behavioral health services to underserved and vulnerable populations, including: children, older adults, veterans and their families, individuals with chronic illnesses, and victims of abuse and trauma.

**HHS programs on aging:** APA supports addressing the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the *Older Americans Act Amendments of 2006*, grants to States for the delivery of mental health screening and treatment services for older individuals and programs to increase public awareness and reduce stigma associated with mental disorders in older individuals.

**Department of Education** – At a minimum, APA encourages the Committee to fund the Javits Gifted and Talented Education Program at the \$10 million level, and the Institute of Education Sciences at \$703.6 million, to provide evidence-based information on effective educational practices.

## Ryan White Medical Providers Coalition

### Testimony Submitted to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

by Alice Thornton, MD

Medical Director, Bluegrass Care Clinic, Lexington, Kentucky, and  
Co-Chair, Ryan White Medical Providers Coalition

April 26, 2015

My name is Dr. Alice C. Thornton, and I serve as Medical Director of the Bluegrass Care Clinic (BCC) at the University of Kentucky Medical Center in Lexington, Kentucky. I submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC), which I Co-Chair. RWMPC is a national coalition of medical providers and administrators who work in clinics supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) at the Health Services and Resources Administration (HRSA). I thank the Subcommittee for its support of Ryan White Part C Programs in FY 15. And while I am grateful for this support, and understand that times are hard, **I request \$225.1 million, or a \$24 million increase for Ryan White Part C programs in FY 16.** While I know that this is a lot of funding, *it is in fact well below the estimated need – in 2014, my clinic alone enrolled 168 new patients into care – a 14 percent increase in one year.* These funds help clinics identify, engage and treat persons living with HIV/AIDS in a way that saves both lives and money. **Additionally, I respectfully request that Congress lift the ban on using federal funds for syringe exchange programs.** These programs are critical to stopping the spread of life-threatening, infectious diseases, such as HIV and viral hepatitis. These programs also help to engage individuals in critically needed medical care, such as drug treatment and primary care.

My Ryan White-funded clinic (BCC) has served as the main source of HIV primary care in the 63 counties of central and eastern Kentucky for the past 24 years. Over half of the

counties served are federally recognized as economically distressed, and BCC cares for 74% of the people living with HIV in the region. Since the BCC received its first Part C grant in 2001, the number of patients has increased by almost 300%. ***To help fund these enormous patient and cost increases, the University incurs an annual deficit of approximately \$1.2 million.***

Most Part C clinics, including BCC, also receive support from other parts of the Ryan White Program (RWP) that help provide medication; additional medical care, such as dental services; and support services, such as case management and transportation -- all essential components of the effective Ryan White HIV care model that results in excellent outcomes.

#### **Ryan White Part C Programs Support Comprehensive, Expert and Effective HIV Care**

Part C of the RWP funds comprehensive, expert and effective HIV care and treatment -- care that is responsible for ***the dramatic decrease in AIDS-related mortality and morbidity***. The RWP has helped develop expert HIV care and treatment programs that have become ***patient-centered medical homes*** for individuals living with this serious, chronic condition. In 2011, a ground-breaking clinical trial, ***named the scientific breakthrough of the year by Science magazine***, found that HIV treatment not only saves the lives of people with HIV, ***but also reduces HIV transmission by more than 96% -- proving that HIV treatment is also prevention.***

The comprehensive, HIV care model that is supported by the RWP achieves positive clinical outcomes with a complex patient population.<sup>1</sup> In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, ***retention in care rates ranged from 87 to 97 percent***. In estimates from the Centers for Disease Control and Prevention (CDC) -- only 37 percent of all people with HIV are in regular care nationally.<sup>2</sup> Once in care,

<sup>1</sup> See *Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities* at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

<sup>2</sup> See CDC's *HIV in the United States: The Stages of Care* <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.

patients served at Ryan White clinics do well— *with 75 to 90 percent having undetectable levels of the virus in their blood. In 2014, 86% of BCC patients had an undetectable viral load, and many of our patients continue to work and remain active community members.*

**Investing in Ryan White Part C Programs Saves Both Lives and Money**

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively *healthy and productive lives* and is more *cost effective*. One study from the Ryan White Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required *2.6 times more health care dollars* than those receiving earlier treatment meeting federal HIV treatment guidelines. *On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs. This is a bargain when compared to the cost of one night in the hospital - \$1000 to \$3000 just for the bed, not to mention the cost of the medical care provided.*

This effective and comprehensive HIV care model, however, is not entirely supported by Medicaid or private insurance. *While most RWP clients have some form of insurance, without the RWP, they would risk falling out of care.* Barriers include poor reimbursement rates; benefits designed for healthier populations that don't cover critical services that dramatically improve health and outcomes for many, such as care coordination; and inadequate coverage for other key services, such as extended medical visits, mental health and substance use treatment.

Because of both the inadequacy of insurance coverage for people with complex conditions like HIV and the fact that some individuals will remain uncovered, even with Affordable Care Act implementation, *fully funding and maintaining the RWP is essential to providing comprehensive, expert and effective HIV care nationwide.* And while RMWPC welcomes the \$4 million increase for Part C programs proposed in the President's FY 16 budget, it is



concerned about the proposal to consolidate Ryan White Part D funding into Part C because:

- ***Parts C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women (including pregnant women) and young people in care.*** With adolescents accounting for 26% of new HIV infections in the U.S., it is critical to target resources to these vulnerable populations.
- ***In some communities, Part D-funded programs are the main providers of HIV care and treatment.*** It is critical to ensure that implementation of any budget proposal does not leave a community without adequate access to effective, comprehensive HIV care and treatment.
- ***It is unclear how the proposed consolidation would be implemented.*** More detail as to what the consolidation process would entail and how it would impact grantees and access to HIV care and treatment is needed. Since most clinics receive funding from multiple parts of the RWP, reducing funding to one part can have damaging and unintended consequences.

At this critical time in the HIV/AIDS epidemic, ***it is essential to maintain overall funding levels for the RWP.*** While the ACA provides important new coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion necessitate a vital, ongoing role for the RWP. Increasing access to and engagement in effective, comprehensive HIV care and treatment is the only way to achieve an AIDS-free generation and reduce the devastating costs of – including lives lost to -- HIV.

#### **Remove the Ban on Using Federal Funding for Syringe Exchange Programs**

**RWMPC strongly urges Congress to lift the ban on federal funding for syringe exchange programs.** RWMPC is committed to evidence-based public health interventions that

both increase access to health care and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major route of transmission for these infectious agents. Because transmission occurs through the sharing or re-use of infected paraphernalia, access to uninfected injection equipment is a key part of infection prevention programs.

Kentucky has one of the highest rates of acute hepatitis C in the country. We have seen a dramatic increase in hepatitis C infections, with a majority occurring in young persons who live in non-urban areas with a history of injection drug use, and previously used opioid agonists such as oxycodone.<sup>i</sup> In our infectious diseases practice, hepatitis C and infections such as endocarditis, have compromised the lives of too many Kentuckians, and we have been frustrated by our inability to employ the full range of effective tools available to prevent infections and help patients address their addiction. These problems also have been seen in Ohio and have advanced even further in neighboring Scott County, Indiana, where HIV infections have topped 130 in just the past few months in a small, rural area that beforehand had under 10 HIV infections each year.

Last month, Kentucky legislators acted decisively to improve public health and the lives of its residents by passing into law a comprehensive set of medical interventions, including expanding access to heroin overdose medication and addiction counseling and treatment. The law also includes a syringe exchange program provision – a well-proven tool for preventing the spread of viral hepatitis, HIV and other infections. The provision will allow local jurisdictions to establish programs that provide clean syringes in exchange for used ones. Congress should permit federal funds to support syringe exchange programs as a key element of infectious disease prevention and as a way to identify and engage individuals in medical care and drug treatment.

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<sup>i</sup> Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis – United States, 2012. Online at: <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm>.



April 29, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

We thank you for your consistent efforts to provide funding for the model comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) programs. We are writing to strongly encourage you to continue to fund this program at the current level in the FY2016 House Labor, HHS Appropriations bill.

The reauthorization of the Higher Education Act in 2008 made an historic commitment to students with intellectual disabilities by establishing new provisions that provided additional access to post-secondary education. One of the most critical provisions made a landmark investment to students with intellectual disabilities by establishing the TPSID programs and National Coordinating Center (NCC).

Since the grant award, the TPSID funding has supported the creation or expansion of programs at 50 colleges and universities serving nearly 2,000 students. These models focus on academic enrichment, socialization, independent living, and employment in order to create, expand or enhance high-quality, inclusive higher education experiences to support positive outcomes for young adults with intellectual disabilities, including paid employment. The comprehensive evaluation system developed by the NCC found that, in just three years, 70% of participating students were involved in career development activities and paid internships. An additional 36% (over 400 students) held paid jobs, of which 89% paid minimum wage or higher, and some students held two or three jobs while they were going to college. These programs are demonstrating that people with I/DD can and will benefit from higher education.

Great strides towards postsecondary education, life in the community and employment are being made through the TPSID programs. However, there are still far too few options available for young people seeking to transition to college and further model development is needed to build on this success. It is essential that the TPSID programs and NCC continue to be funded. On behalf of the CPSD, we strongly urge your support in the FY2016 appropriations bill. If you have any questions, please let Laura Kaloi with CPSD know. She can be reached at her email, [lkaloi@wpilc.net](mailto:lkaloi@wpilc.net).

Sincerely,

Denise Marshall  
Co-Chair  
CPSD Youth in Transition Workgroup  
Council of Parent Attorneys and Advocates

Barbara Trader  
Co-Chair  
CPSD Youth in Transition Workgroup  
TASH

CPSD is a national, family-driven and consumer-led advocacy network of 22 national organizations. These organizations have come together to bring about a significant modernization of the federal system of services and supports for persons with disabilities. We focus on high-impact public policy and systems reform to improve the employment and socio-economic outcomes of citizens with intellectual and developmental disabilities promoting the effective transition of students with developmental disabilities into adulthood by preparing them to obtain optimal outcomes in education, employment, economic advancement, and independent living.

*The National AHEC Organization supports and advances the AHEC Network to improve health by leading the nation in the recruitment, training and retention of a diverse health workforce for underserved communities.*

**STATEMENT OF ROBERT TRACHTENBERG, MS  
CHIEF EXECUTIVE OFFICER  
NATIONAL AHEC ORGANIZATION  
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**REGARDING FISCAL YEAR 2016 APPROPRIATIONS  
FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION'S TITLE VII  
AREA HEALTH EDUCATION CENTER PROGRAM**

**SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH  
AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

The members of the National AHEC Organization (NAO) are pleased to submit this statement for the record recommending **\$35 million in FY 2016 for the Area Health Education Center (AHEC) program** authorized under Titles VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). The NAO is the professional organization representing AHECs. The AHEC Program is an established and effective national primary care training network built on committed partnerships of 56 medical schools and academic health science centers. Additionally, 253 community-based AHECs within 48 states and tens of thousands of community practitioners are affiliated with the AHEC's national clinical training network.

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of health care services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments. The AHEC program would be the mechanism to recruit providers into primary health careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. Area Health Education Centers are the workforce development, training and education machine for the nation's health care safety-net programs. The AHEC program is focused on improving the quality, geographic distribution and diversity of the primary care healthcare workforce and eliminating the disparities in our nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

*The National AHEC Organization supports and advances the AHEC Network to improve health by leading the nation in the recruitment, training and retention of a diverse health workforce for underserved communities.*

The Area Health Education Center program is effective and provides vital services and a national infrastructure. Nationwide, over 379,000 students have been introduced to health career opportunities, and over 33,000 mostly minority and disadvantaged high school students received more than 20 hours each of health career exposure activities. Over 44,000 health professions students received training at 17,530 community-based sites, and furthermore; over 482,000 health professionals received continuing education through AHECs. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal Clinics and Public Health Departments.

### **Justification for Recommendations**

The AHEC network is an economic engine that fuels the recruitment, training, distribution, and retention of a national health workforce. AHEC stands for JOBS.

- AHECs are critical in the recruitment, training, and retention of the primary care workforce.
- Research has demonstrated that the community-training network is the most effective recruitment tool for the health professions and those who teach remain longer in underserved areas and communities.
- AHECs are in nearly 90% of all counties in the United States.
- With the aging and growing population, the demand for primary care workforce is far outpacing the supply.
- AHECs continue to educate and train current workforce, as well as recruiting and preparing future workforce
- In Program Year 2013-2014, AHEC's had 731,515 active participants training in their programs
  - 299,932 students were exposed to health careers with the intent to pursue post-secondary education in primary healthcare professions through AHEC's pipeline programs
  - AHECs facilitated 40,591 rotations in clinical training to improve readiness, willingness, and ability of health professions trainees to serve in primary care, and rural and underserved communities
  - 19,048 health professions students were placed in rural and underserved locations
    - 10,643 were medical students
    - 8,405 were associated health professions students
  - 412,535 participants in continuing education programs learned how to address key issues in health professional shortage areas to improve quality of healthcare for medically underserved and health disparities populations
- Approximately 459,272 health professions students engaged in AHEC-supported programs between July 2013 and December 2014. Of these students engaged in AHEC-supported structured programs, 74% were from disadvantaged backgrounds, 54% were from rural backgrounds, and 27% were under-represented minorities (URM).
- The AHEC network's outcomes are the backbone of the nation's community-based health professions training, with a focus on training primary care workforce.

*The National AHEC Organization supports and advances the AHEC Network to improve health by leading the nation in the recruitment, training and retention of a diverse health workforce for underserved communities.*

- Continued funding for the AHEC program is necessary as demonstrated by 1) a growing unmet need for primary care doctors in rural areas, and 2) the use of the national network of AHEC programs to carry out administrative priorities.
  1. The National Health Service Corps (NHSC), has been mentioned as a program that addresses the priority of increasing diversity in the health professions workforce in underserved and rural areas and addresses the end of the pipeline. The AHEC program engages in pre-pipeline, pipeline, and post-pipeline activities that works to move individuals through a health careers pathway and beyond, with a special focus on primary care doctors.
  2. The national network of the AHEC program has successfully completed the following:
    - Trained 13,000+ primary care providers nationwide in OIF/OEF/OND Veteran's behavioral and mental health, substance abuse, traumatic brain injury and post-traumatic stress for those Veterans not utilizing the VA system
    - Worked with the Food and Drug Administration to educate healthcare professionals nationwide on proper opioid prescribing habits to address the epidemic of prescription drug abuse
    - Developed functional linkages between Bureau of Primary Care and Bureau of Health Professions Programs. AHECs have partnerships with over 1,000 Community Health Centers nationally to recruit, train, and retain health professionals who have the cultural and linguistic skills to serve in HRSA-designated underserved areas
    - Delivered state customized training regarding Affordable Care Act activities, such as increasing the enrollment of individuals and educating primary care providers nationwide on state health insurance exchanges



**STATEMENT OF ANTHONY CASTALDO  
PRESIDENT, U.S. HEREDITARY ANGIOEDEMA ASSOCIATION**

**REGARDING FISCAL YEAR 2016 APPROPRIATIONS  
FOR THE NATIONAL INSTITUTES OF HEALTH AND  
THE CENTERS FOR DISEASE CONTROL AND PREVENTION**

**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
AND RELATED AGENCIES**

**APRIL 29, 2015**

**SUMMARY OF FY16 RECOMMENDATIONS**

- 1) Provide \$32 billion for the National Institutes of Health (NIH)
- 2) Support the NIH hereditary angioedema research portfolio
- 3) Encourage the Centers for Disease Control and Prevention (CDC) to advance hereditary angioedema education and awareness

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) regarding fiscal year 2016 (FY16) funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). On behalf of U.S. HAEA, I urge Congress to support hereditary angioedema research and public awareness.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of

excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50% of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

#### **RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH**

*U.S. HAEA recommends that Congress provide an overall funding level of \$32 billion for NIH in FY16. In addition, U.S. HAEA urges Congress to include recommendations in accompanying committee reports emphasizing the importance of advancing HAE research per the findings of the October 2014 scientific conference, Expanding Boundaries of our HAE Knowledge.*

In October 2014, the NIH National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Sciences (NCATS), and U.S. HAEA partnered on the state-of-the-science conference, *Expanding Boundaries of our HAE Knowledge*. This conference brought together top HAE researchers as well as other medical researchers across disciplines in order to identify promising avenues for future research. NIH should capitalize on this conference by issuing requests for applications or other opportunities for HAE research based on the findings of the conference.

As a rare disease community, HAE patients are also stakeholders of the Office of Rare Diseases Research (ORDR) and may benefit from programs like the Therapeutics for Rare and



Neglected Diseases (TRND) program. U.S. HAEA also urges Congress to robustly support NCATS and the NIH rare disease portfolio in FY16.

#### **CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS**

*In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in FY16.*

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, patients are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment, and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, the use of available treatments can help patients lead a productive life. Education and awareness is needed to reach patients and providers with this message.

Thank you for the opportunity to present the views of the HAE patient community. I hope Congress will support research and education on HAE.

**Eldercare Workforce Alliance**  
**Outside Witness Testimony - Fiscal Year 2016 Appropriations**  
 Subcommittee Labor, Health and Human Services, Education and Related Agencies  
 Committee on Appropriations  
 United States House of Representatives  
 April 29, 2015

Written Testimony\*\* Regarding Funding Requests for Eldercare Workforce Programs  
 of the Department of Health and Human Services

Submitted on behalf of the Eldercare Workforce Alliance  
 2519 Connecticut Avenue, NW, Washington, DC 20008  
 202-505-4817 kbarnett@eldercareworkforce.org

By

Nancy Lundebjerg, MPA  
 Alliance Co-Convenor  
 (212) 308-1414

Michèle Saunders, DMD, MS, MPH  
 Alliance Co-Convenor  
 (210) 567-7439

Mr. Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee:

We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 31 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee begins consideration of funding for programs in FY 2016, the Alliance\*\* urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard. We hope you will support a total of \$44.7 million for geriatrics programs in Title VII and Title VIII of the Public Health Service Act, \$197.5 million for programs administered by the Administration for Community Living (ACL), \$1.67 billion to support the research efforts of the National Institute on Aging (NIA), and \$6.7 million for additional workforce programs in the Health Resources and Services Administration (HRSA).

Today's health care workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. Without

*\*\*The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.*

a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, HRSA has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities. Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately \$450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 71% increase from today's 41 million older adults. That is why Title VII and Title VIII geriatrics programs, ACL programs that support family caregivers, and the research efforts of NIA are so critical to ensuring there are skilled eldercare workers and well-supported family caregivers available to meet the complex and unique needs of older adults. Specifically, we recommend the following levels:

- **\$44.7 million for Title VII and Title VIII Geriatric Workforce Enhancement Program;**
- **\$197.5 million for Family Caregiver Support Programs; and**
- **\$6.7 million for additional workforce programs from HRSA.**

EWA specifically requests the following levels of funding:

**Title VII and Title VIII Geriatric Workforce Enhancement Program: Request: \$44.7 Million**

- The Geriatrics Workforce Enhancement program is the only federal program that increase the number of faculty with geriatrics expertise in a variety of disciplines who provide training in clinical geriatrics, including the training of interdisciplinary teams of health professionals. In December 2014, the Health Resources and Services Administration announced they will combine the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental

Health Providers programs into the Geriatrics Workforce Enhancement Program to provide greater flexibility to grant awardees by allowing applicants to develop programs that are responsive to specific interprofessional geriatrics education and training needs of their communities. In May 2015, HRSA plans to make 40 awards. Our modest funding request increase would allow for 50 awards.

- Title VII Geriatrics Workforce Enhancement Program: **EWA requests \$34.4 million.** This program provides health professions schools and training programs support to provide interprofessional geriatrics education and training responsive to specific needs of their communities.
- Alzheimer's Disease Prevention, Education, and Outreach Program: **EWA requests \$5.3 million.** These funds allow HRSA to expand efforts to provide interprofessional continuing education to health care practitioners on Alzheimer's disease and related dementias, utilizing the newly developed Geriatric Workforce Enhancement Programs.
- Comprehensive Geriatric Education Program: **EWA requests \$5 million.** This program provides support to train and educate individuals in providing geriatrics care for the elderly. Program goals are accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees in geriatric nursing, long-term care, gero-psychiatric nursing or other nursing areas that specialize in the care of the elderly population.

**Administration for Community Living Family Caregiver Support: Appropriations Request: \$197.5 million**

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

- Family Caregiver Support Services: **EWA requests \$161 million.** This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that assist family and informal caregivers in caring for their loved ones.
- Native American Caregiver Support: **EWA requests \$7 million.** This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services.
- Alzheimer's Disease Support Services: **EWA requests \$9.5 million.** One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. It funds evidence-based interventions and expands the dementia-capable home and community-based services.
- Lifespan Respite Care: **EWA requests \$5 million.** This program funds grants to improve access to respite care for family caregivers of children or adults with special needs.
- Family Support Initiative: **EWA requests \$15 million.** The new initiative will encourage use of community assets and opportunities to help families reduce stress, improve emotional well-being, develop support skills and knowledge, and plan for the future. Special attention will be given to efforts that assist families with balancing workforce participation and caregiving responsibilities, and those facing the dual demands of caring for older parents while raising children and/or supporting a family member with disabilities.

**National Institute on Aging: Appropriations Request: \$1.67 billion**

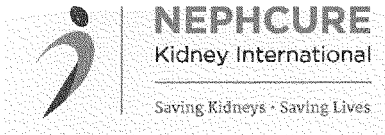
The National Institute on Aging, one of the 27 Institutes and Centers of the National Institute of Health, leads a broad scientific effort to understand the aging process in order to promote the health

and well-being of older adults. Funding will aid in researching training initiatives for the workforce that cares for older adults and research on physician-family communications during end-of-life and critical care.

**Additional Workforce Programs under HRSA: Appropriations Request: \$6.7 million**

- National Health Care Workforce Commission: **EWA requests \$3 million.** The National Health Care Workforce Commission, established by the ACA, plays a central role in formulating a national strategy for bolstering the health care workforce in order to meet the needs of the burgeoning numbers of older Americans. On behalf of the members of the Eldercare Workforce Alliance, thank you for your past support for geriatric workforce programs.
- Geriatric Career Incentive Awards Program: **EWA requests \$3.3 million.** Congress authorized this new program through the ACA. Assuming it is extended, these funds foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management.
- Training Opportunities for Direct Care Workers: **EWA requests \$3.4 million.** In the ACA, Congress approved a program administered by HHS that will offer advanced training opportunities for direct care workers. While this vital training program was left out of President Obama's budget, EWA believes Congress must extend and fund it to create new employment opportunities by offering new skills through training.

We ask that you join us in supporting the geriatrics workforce at this critical time – for all older Americans deserve quality care, now and in the future.

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**STATEMENT OF  
 IRVING SMOKLER, PH.D.  
 PRESIDENT AND FOUNDER  
 NEPHCURE KIDNEY INTERNATIONAL**

**ON BEHALF OF  
 NEPHCURE KIDNEY INTERNATIONAL**

**FISCAL YEAR 2016 APPROPRIATIONS FOR THE  
 NATIONAL INSTITUTES OF HEALTH**

**SUBMITTED TO THE  
 HOUSE COMMITTEE ON APPROPRIATIONS  
 SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,  
 AND RELATED AGENCIES**

**APRIL 29, 2015**

**SUMMARY OF RECOMMENDATIONS FOR FY16:**

- 1) PROVIDE \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)**
- 2) PROVIDE A CORRESPONDING INCREASE TO THE NIH INSTITUTES AND CENTERS**
- 3) SUPPORT THE EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK, THE OFFICE OF RARE DISEASES RESEARCH (ORDR) AND THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD) BY FUNDING MORE RESEARCH PROPOSALS FOR PRIMARY GLOMERULAR DISEASE**

Thank you for the opportunity to present the views of NephCure Kidney

International regarding research on idiopathic focal segmental

glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure

is the only non-profit organization exclusively devoted to fighting FSGS and

the NS disease group. Driven by a panel of respected medical experts and a dedicated band of

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 NephCure.org • [info@nephcure.org](mailto:info@nephcure.org) • 1-866-NEPHCURE

patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the



Medicare program alone spent \$26.8 billion, 7.9% of its entire budget, on ESRD. In 2005, FSGS accounted for 12% of ESRD cases in the U.S., at an annual cost of \$3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in federal health care costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

#### **ENCOURAGE FSGS/NS RESEARCH AT NIH**

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in health care costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the *Rare Disease Clinical Research Network*. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. **NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.**

NIDDK recently initiated the Cure Glomerulonephropathy Network (Cure GN), a multicenter five-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. **NephCure recommends that the subcommittee encourage NIDDK to continue to support CureGN as well as other primary glomerular disease program announcements.**

It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in FY13. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. **NephCure asks the subcommittee to encourage NIMHD to continue to study FSGS/NS, including the APOL1 gene.**

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact NephCure Kidney International if additional information is required.

# THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

## Request to Approve President's FY2016 Budget Request for the Bureau of Labor Statistics

Andrew Reamer, Research Professor  
April 29, 2015

Submitted to House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

I request that the Subcommittee approve in full the President's FY2016 budget request of \$632,737,000 for the Bureau of Labor Statistics of the Department of Labor.

The work of the U.S. Bureau of Labor Statistics (BLS) is essential to the U.S. economy's proper functioning and to the sustained material well-being of the nation's residents. Access to current, reliable BLS statistics are needed to inform intelligent public, private, and personal decisions on a daily basis. BLS statistics include those on employment and unemployment, compensation, prices, consumer expenditures, industrial productivity, and occupational health and safety. Decision-makers relying on these data include:

- **legislative bodies**, including Congress, state legislatures, and county and city councils;
- **federal policymakers** such as the Federal Reserve, the National Economic Council, the Office of Management and Budget (OMB), the U.S. International Trade Commission, the Office of the U.S. Trade Representative, and the Departments of Treasury, Commerce, Labor, Education, Veterans Affairs, Housing and Urban Development, Energy, and Health and Human Services;
- **state and local government agencies** in fiscal management, economic and workforce development, education, transportation, social services, housing, and health care; and
- tens of millions of **students and workers**, millions of **small and large businesses**, and thousands of **education and training institutions**.

BLS data's contribution to the growth and stability of the nation's \$17 trillion economy is orders of magnitude greater than the agency's annual budget.

Recently, BLS's ability to contribute to national economic growth and development has been hampered by substantial cuts made by Congress to agency's annual budget requests for FY2011 through FY2015. In real terms, Congress chopped the BLS budget by 10 percent between FY2010 and FY2015. In response, the agency has been forced to substantially scale back its work. In particular, it has:

- **eliminated** several long-standing statistical programs—such as Mass Layoff Statistics and International Labor Comparisons;

- **reduced the reliability** of others—such as the Quarterly Census of Employment and Wages;
- **been unable to implement** planned statistical program improvements—such as creating time series of occupational employment by state and metropolitan area; and
- **put users on notice** that other programs—including Export Price Indexes, a Principal Federal Economic Indicator—would be eliminated if additional funding were not found.

Congress's recent actions are in contrast to those it took in FY2009, when its appropriations for BLS exceeded the budget request by one percent, and FY2010, when it matched the budget request. While the amount of funds Congress has saved through its recent cuts in the BLS budget request (between \$21 million and \$41 million annually) is very small in the context of a \$3.5 trillion in annual federal expenditures, the negative consequences to the quality and reliability of the federal statistical system, on which the health of the \$17 trillion economy and the employment conditions of 160 million adults depends, are quite substantial. To some degree, each type of decision-maker noted above is "flying blind," making choices that have significant economic consequences in the absence of current, reliable, readily accessible information.

As is the case with any federal agency, BLS designs, carries out, and seeks appropriations for its multiple programs in the context of a series of congressional directives specified in the U.S. Code. It seems reasonable and appropriate that Congress provide BLS with the funds necessary for that agency to fulfill its congressionally-mandated tasks. It also seems appropriate that if Congress chooses to not provide funds sufficient for these tasks, it identify the specific legal mandates it wants BLS to ignore and communicate such choices to the authorizing committees with jurisdiction over BLS.

**So that the Subcommittee can make informed decisions regarding which legal mandates, if any, it wants BLS to ignore, I summarize and provide the citations for BLS's various legal mandates below:**

**BLS's primary authorizing statute**, its "organic law," gives it broad authority to develop statistical programs. This statute, first written in 1888 and last amended in 1913, identifies the broad purposes, boundaries, and topics of BLS activity:

The general design and duties of the Bureau of Labor Statistics shall be to acquire and diffuse among the people of the United States useful information on subjects connected with labor, in the most general and comprehensive sense of that word, and especially upon its relation to capital, the hours of labor, the earnings of laboring men and women, and the means of promoting their material, social, intellectual, and moral prosperity. (29 USC 1)

This general mandate provides the rationale and context for a series of much more specific activities identified elsewhere in law. The focused mandates given by Congress to BLS can be organized into five groups, sketched out below:

- 1) **Nationwide Workforce and Labor Market Information System** – The Secretary of Labor is directed to develop, maintain, and continuously improve, in cooperation with the states, a nationwide workforce and labor market information system that facilitates federal, state, and local policy and program design, implementation, and evaluation; labor market research; and informed decision-making by employers, workers, students, educational agencies, and workforce investment boards (29 USC 491-2 and 29 USC 2864(d)(2)(E)).

The U.S. Code gives BLS five additional mandates inside this broad one:

- a) Collect, collate and report at least once each year full and complete statistics on the **conditions of labor** (29 USC 2);
- b) Collect, collate, report, and publish **monthly and annual employment and wage statistics** by detailed industry and geography (29 USC 2);
- c) Operate statistical programs essential for development of . . . national statistical series, including those related to **employment and unemployment** (29 USC 491-1);
- d) Develop methods for estimating **Hispanic unemployment** (29 USC 8); and
- e) Conduct an annual study of **veterans' unemployment** (38 USC 4110A).

- 2) **Determination of Federal Pay by Locality** – Congress declares a policy that: federal pay for employees under the General Schedule be based on equal pay for equal work; federal pay distinctions be maintained in line with work and performance distinctions; within any local pay area, federal pay rates be compatible with non-federal pay rates for the same levels of work; and pay disparities between federal and non-federal employees should be eliminated (5 USC 5301). In line with these principles, **federal pay rates are to be determined on the basis of a number of specified data sources**, including these BLS products:

- a) Employment Compensation Index (national)
- b) National Compensation Survey (pay to non-federal workers by occupation and work level, by pay locality)
- c) Unemployment rate (national)
- d) Consumer Price Index (national)
- e) Producer Price Index (national)

- 3) **Reports on Industrial Production and Productivity** – BLS is directed to:

- a) Collect, collate and report at least once each year full and complete statistics on the **products of the nation's labor force and the distribution of these products** (29 USC 2);

- b) At intervals of not less than two years, . . . report **the general conditions of production of the nation's leading industries** (29 USC 4); and
  - c) Make continuing studies of **productivity and labor costs** in the manufacturing, mining, transportation, distribution, and other industries (29 USC 2b).
- 4) **Imports Monitoring** – The Secretary of Labor and the Secretary of Commerce are directed to monitor imports of goods and services to identify **changes in volume of imports and the impacts on production and employment, by geography** (19 USC 2393(a)).
- 5) **Occupational Health and Safety Statistics** – The Secretary of Labor is directed to develop and maintain **an effective program of collection, compilation, and analysis of occupational safety and health statistics**. The program should provide accurate statistics on work injuries and illnesses that include all disabling, serious, or significant injuries and illnesses, whether or not involving loss of time from work, and which involve medical treatment, loss of consciousness, restriction of work or motion, or transfer to another job (29 USC 673(a)).

I appreciate the opportunity to provide testimony to the Subcommittee, hope it found this testimony useful, and look forward to the results of its forthcoming markup.



**STATEMENT OF LEE CLAASSEN  
EXECUTIVE DIRECTOR  
INTERSTITIAL CYSTITIS ASSOCIATION**

**REGARDING FISCAL YEAR 2016 APPROPRIATIONS  
FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION  
AND NATIONAL INSTITUTES OF HEALTH**

**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES**

**APRIL 29, 2015**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2016:**

- **PROVIDE \$1 MILLION FOR THE IC EDUCATION AND AWARENESS PROGRAM AND THE IC EPIDEMIOLOGY STUDY AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**
- **PROVIDE \$7.8 BILLION FOR CDC**
- **PROVIDE \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND PROPORTIONAL INCREASES ACROSS ALL INSTITUTES AND CENTERS**
- **SUPPORT NIH RESEARCH ON IC, INCLUDING THE MULTIDISCIPLINARY APPROACH TO THE STUDY OF CHRONIC PELVIC PAIN (MAPP) RESEARCH NETWORK**

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC is limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.



**IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC**

***ICA recommends a specific appropriation of \$1 million in fiscal year 2016 (FY16) for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.***

In December 2014, CDC switched the focus of the IC program from education and awareness to an epidemiology study. The IC community is concerned that eliminating education and awareness activities is detrimental to patients and their families. The CDC IC Education and Awareness Program is the only federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in FY16.

The IC Education and Awareness program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provided patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available.

Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

## **IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH**

***ICA recommends a funding level of \$32 billion for NIH in FY16. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.***

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes, including epidemiology. The MAPP Study has expanded in its second phase to include cross-cutting researchers and researchers are currently identifying different phenotypes of the disease. Phenotype information will allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Integrative Health (NCCIH). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

Thank you for the opportunity to present the views of the interstitial cystitis community.

**ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES**

**TESTIMONY**

**BEFORE THE**

**HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**APPROPRIATIONS**

**PREPARED BY**

**Andrew Imparato  
Executive Director, Association of University Centers on Disabilities (AUCD)  
1000 Wayne Ave.  
Suite 1000  
Silver Spring, MD 20910**

**April 29, 2016**

The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Network members consist of:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Intellectual Developmental Disabilities (AIDD)
- 43 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- 15 Intellectual and Developmental Disability Research Centers (IDDRC), most of which are funded by the National Institute for Child Health and Development (NICHD)

To frame the need for the AUCD network in “people terms,” approximately 19% or almost 1 in 5 Americans have a disability. This translates to 57 million citizens.<sup>1</sup> Developmental disabilities are disabilities that significantly affect three or more activities of daily living, occur prior to the age of 22, and include such disabilities as autism, behavioral disorders, cerebral palsy, brain injury, fragile X, Down syndrome and other genetic syndromes, fetal alcohol syndrome, intellectual disabilities and spina bifida. Disabilities place individuals at risk living in poverty<sup>1</sup>, having significant secondary health risks, and for being un- and under-employed. Compared to other populations in the United States who suffer from health disparities, individuals with disabilities have the highest percentage of self-rated poor or fair health and, the highest proportion of sedentary lifestyle, smoking, obesity, and diabetes.<sup>2</sup> Only 41% of individuals with disabilities, ages 21-64 years, are employed and subgroups of people with disabilities, such as those with intellectual disabilities have a workforce participation rate of less than 20%. Underserved racial and ethnic populations with disabilities, i.e., African American, Hispanic/Latino and Native Americans have even higher percentages of delayed diagnosis, poor health, lack of access to health and education services, and unemployment.<sup>2</sup> Without increased funding, the population of individuals with disabilities, especially those from underserved populations, will continue to demonstrate disparities in receiving early identification, optimum education, and treatment, thereby increasing the lifetime cost of services.<sup>2,3</sup> Through the clinical care, teaching, training, research, and advocacy efforts of the AUCD network, the number of individuals with disabilities who are living in poverty, have unmet health needs, and/or are unemployed can be reduced.

All of AUCD’s member Centers have unique strengths in research, education, and training that they share through partnerships with the programs and individuals whom they serve. AUCD’s member centers exist in all 50 US states and territories provide a wealth of resources to the nation. These resources include exemplary educators who train the next generation of professionals; clinical, education, and research leaders who work in partnership with individuals with disabilities to advocate for and promote inclusion and optimal functioning, and the ability

to address the needs of family members in areas such as early care and education, primary health care, special education, and innovative housing and employment programs. AUCD centers excel in basic and translational research, developing assays for early detection of and treatment for neurodevelopmental diseases, creating demonstration programs, advocating for systemic reform to optimize functioning, and analyzing the impact of policies. AUCD members serve as professional resources for local, state, and federal agencies. The synergy created by the AUCD network members, supported by the AUCD infrastructure, allows innovative interdisciplinary collaboration, promoting rapid dissemination of advances in identification, prevention, and treatment to the population and communities most in need—thus affecting more lives than any one program could touch. I'd like to summarize for you the scope of each program

### **Leadership Education in Neurodevelopmental Disabilities (LEND)**

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs provide advanced training to students from multiple disciplines including neurology, audiology, genetics, nursing, nutrition, occupational therapy, pediatrics, pediatric dentistry, physical therapy, psychology, psychiatry, social work, rehabilitation counseling, special education, and speech-language pathology. With the guidance of expert professional faculty these trainees learn how to identify and treat a wide range of developmental disabilities, including autism spectrum disorders, speech-language disorders, hearing and vision impairments, cerebral palsy, epilepsy, spina bifida, fragile X syndrome, Down syndrome and other intellectual disabilities, and a wide range of genetic and metabolic disorders. Nationally, there are tremendous shortages of personnel trained to screen, diagnose and treat individuals with developmental disabilities, and as a result, families often have to wait months to get a comprehensive diagnosis and evidence-based interventions.

The LEND network is currently made up of 43 programs in 37 states. According to the Congressionally mandated Report to Congress on the Combating Autism Act (2014), the LEND programs have collectively made significant strides toward improved screening and diagnosis of autism among younger children and helped train a variety of healthcare professionals who treat a number of different developmental and intellectual disabilities.

In 2006 the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis on the early identification, diagnosis and treatment of children with autism spectrum disorders because of the significantly rising prevalence of children with ASD in the US. This law was reauthorized in 2011 and again in 2014 as the Autism CARES Act (P.L. 113-157). The law recognizes the benefits of the LEND network to address this significant public health issue by authorizing the expansion of the network. The law intends to expand the LEND

programs to all states by gradually adding LEND programs in each of the thirteen states that currently do not have such a program.

For Fiscal Year 2016, AUCD is requesting \$30 million, a \$2 million increase for the LEND program. This is the amount that was authorized (but never reached) for FY 2011 under the original Combating Autism Act. This additional funding would provide resources for up to two new LEND programs in states that do not have one and increase funding for existing LEND programs. The increase would expand the number of sites and professionals to screen, diagnose, and provide interventions to individuals with autism spectrum disorder and other developmental disabilities as intended by the law and will increase the capacity to address the racial and ethnic delays in diagnosing these disabilities.

### **University Centers for Excellence in Developmental Disabilities (UCEDD)**

Authorized under the DD Act, the Administration for Community Living (ACL) supports a network of 67 University Centers for Excellence in Developmental Disabilities (UCEDD) that provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. The national network of UCEDDs are well situated in all 50 states and territories to facilitate communication across agencies, schools, and other providers as they are accustomed to blending resources and have had extensive experience working with multiple state and local agencies, interdisciplinary academic departments and community partners.

For Fiscal Year 2016, AUCD has requested \$39 million to provide continued support to maintain the existing 67 UCEDDs. Due to the funding formula in the Developmental Disabilities Act that requires appropriated funds to provide cost of living adjustments (COLA) to Centers before funding National Training Initiatives (NTI) and technical assistance to Centers, this level of funding is necessary to support the core functions of the Centers in addition to being able to funding emerging national issues, such as transition from school to postsecondary education, service, and/or integrated employment, and others identified by the DD network. Continued funding will also be used to leverage the UCEDD's existing relationship with state agencies, disability organizations and youth with disabilities to help implement provisions under the recently passed Workforce Innovations and Opportunities Act, such as improving comprehensive transition outcomes from adolescence to adulthood in ways that lead to post-secondary education and meaningful employment.

### **Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers (IDDRC)**

For over 40 years, the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDRC) have been at the forefront of basic and translational research on human brain development. In the early years of the IDDRC network, investigators identified

the basic processes by which the brain is formed. In the years since, the genes and cellular mechanisms that promote normal development have been discovered and the genetic and environmental causes of disrupted development causing intellectual and developmental disorders revealed. Based on this work, we are now at the dawn of an era when we can treat the basic mechanisms that cause intellectual and developmental disorders and not just the symptoms. As an example, about 15 years ago IDDRC investigators discovered that mutations of the MeCP2 gene cause Rett syndrome, a neurodegenerative disorder that afflicts young girls causing autism, epilepsy, altered breathing, intellectual disability and impaired motor function. An initial clinical trial was just completed shows improved breathing and behavior through treatment with IGF-1, a molecule whose function was discovered to be altered by the MeCP2 mutation. Similar approaches are emerging to treat other neurodevelopmental disorders, often manifest with autism and/or intellectual disability, with a goal to reverse the process, to enable the child to grow and develop to achieve with the absolute highest quality of life. New insights have also been gained into the causes of intellectual and developmental disabilities in children exposed to harmful environmental exposures, with approaches implemented to lessen these exposures and their impact on the developing brain. For newborn infants, neuroprotective strategies have been developed and implemented to lessen the effects of brain injury, enhancing the developmental potential of these highly vulnerable children.

### **Collaboration**

By working together, UCEDDs, LENDs, and IDDRCs engage in research that informs best treatment practices and national policy. The network emphasizes national implementation of innovations in disability-related education, health care, and supports and services.

One family's partnership with Tennessee's Vanderbilt Kennedy Center, which houses an IDDRC, UCEDD, and LEND, illustrates a lifelong relationship of engagement in the areas of training, research, and service. The mother began interactions with the Center when she was a graduate student training at Vanderbilt Peabody College. After embarking upon a career in teaching, she and her husband adopted a son, who would later be diagnosed at Vanderbilt with autism and bi-polar disorder. The child grew older and entered an inclusive pre-school on campus. During his school years, he was involved with research projects, and summer camps. His parents enrolled in a Center research project on mindfulness-based stress reduction offered to parents who have sons or daughters with disabilities. Their son would go on to perform and learn valuable social skills through the Center's SENSE Theatre project. This year, he will graduate from Next Steps at Vanderbilt, the Center's postsecondary education program for students with intellectual and developmental disabilities. While a Next Steps student, he completed an internship with the preschool he attended as a child. Several of his Next Steps classes were taught by current Center trainees, who like his mother, will go on to support individuals with

disabilities and work to improve their quality of life in a variety of settings. With the Center's lifespan approach, this partnership is sure to continue as needs and opportunities arise. This mother said, "I do not know what my husband and I would have done without the practical and researched-based wisdom of the Vanderbilt Kennedy Center."

In conclusion, the collaborative network of AUCD member organizations provide comprehensive services with the goal of optimizing health, education, functioning, inclusion, and well-being for individuals with disabilities and their families. With increased funding the AUCD member organizations have the potential to expand comprehensive services to address the health, education, housing, and employment needs of this severely underserved and vulnerable population of United States citizens. There is more to be done to allow AUCD to become the model proactive system of comprehensive care that it has the potential to be. Investments in these activities now will result in significantly decreased costs for future generations.

1. Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports: Report Released to Coincide with 22nd Anniversary of the ADA [press release]. Washington DC: United States Census Bureau, July 25, 2012 2012.
2. Drum C, McClain MR, Horner-Johnson W, Taitano G. *Health disparities chart book on disability and racial and ethnic status in the United States*. Durham, NH 2011 2011.
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**DAVID T. RUBIN, MD  
NATIONAL SCIENTIFIC ADVISORY COUNCIL  
CHAIR, GOVERNMENT & INDUSTRY AFFAIRS COMMITTEE**

**STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA**

**507 CAPITOL COURT, N.E. SUITE 200  
WASHINGTON, D.C. 20002  
(202) 544-7499**

**SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION, AND RELATED AGENCIES**

**REGARDING FISCAL YEAR 2016 APPROPRIATIONS FOR THE  
NATIONAL INSTITUTES OF HEALTH AND THE  
CENTERS FOR DISEASE CONTROL AND PREVENTION**

**SUMMARY OF FY16 RECOMMENDATIONS**

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH).  
INCREASE FUNDING FOR THE NATIONAL INSTITUTE OF DIABETES AND  
DIGESTIVE AND KIDNEY DISEASES (NIDDK).**
- 2) CONTINUED FOCUS ON DIGESTIVE DISEASE RESEARCH AND  
EDUCATION AT NIH, AND SUPPORT FOR THE INFLAMMATORY BOWEL  
DISEASE (IBD) PORTFOLIO**
- 3) \$1,000,000 FOR THE CENTERS FOR DISEASE CONTROL AND  
PREVENTION'S (CDC) IBD EPIDEMIOLOGY ACTIVITIES.**

Thank you for the opportunity to submit testimony on behalf of the Crohn's and Colitis Foundation of America (CCFA). CCFA has remained committed to its mission of finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for over 46 years.

Impacting an estimated 1.1.6 million Americans, 30% of whom are diagnosed as children, the Inflammatory Bowel Diseases (IBD) (including Crohn's disease and ulcerative colitis) are chronic immune disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBDs represent a major cause of morbidity from digestive illness and have a devastating impact on both patients and their families.

The social and economic impact of digestive disease is enormous. Digestive disorders afflict approximately 65 million Americans. This results in an estimated 50 million visits to physicians,

over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year. **Importantly, IBD accounts for an estimated \$28 billion annually, reflecting the per capita disproportionately expensive care that IBD patients require.**

CCFA would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

### **NATIONAL INSTITUTES OF HEALTH**

For NIH, CCFA recommends:

- \$32 billion for NIH
- \$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)

We at CCFA respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

In recent years, researchers have made substantial progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. CCFA applauds NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. CCFA also commends NIDDK for hosting a conference on inflammatory bowel disease in children which could lead to further research in this area. The Committee urges NIDDK to continue efforts to identify the etiology of the disease in order to inform the development of cures for inflammatory bowel disease.

### **CENTERS FOR DISEASE CONTROL AND PREVENTION**

For CDC, CCFA encourages:

- CDC to continue to support a nationwide IBD surveillance and epidemiological program at \$1 million for FY16 to expand current efforts to identify the etiology of the disease and implement preventive measures

CDC, in collaboration with a nationwide, geographically diverse network of large managed health care delivery systems, has led an epidemiological study of IBD to understand IBD incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, CCFA, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, OSCAR investigators have recruited 22 private-practice groups and hospital based physicians in Rhode Island and are that enrolling newly

diagnosed patients into the registry. This study found an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in Inflammatory Bowel Disease Journal, April 2007.

- Over the course of the initial 3-year epidemiologic collaboration, CDC laboratory scientists and epidemiologists worked to improve detection tools and epidemiologic methods to study the role of infections (infectious disease epidemiology) in pediatric IBD, collaborating with extramural researchers who were funded by an NIH research award.
- Since 2006, CDC epidemiologists have been working in conjunction with CCFA and a large health maintenance organization to better understand the natural history of IBD as well as factors that predict the course of disease.

CCFA commends CDC for implementing a robust IBD epidemiology study and communicating study results with the public. CCFA supports the continued exploration of the disease burden of IBD, and communication of these findings to patients and providers in an effort to improve current interventions and inform best public health practices in managing IBD.

## **CONCLUSION**

CCFA understands the challenging budgetary constraints that this Subcommittee is operating under, yet we hope you will strongly consider the tremendous benefits to be gained by supporting these valuable programs at the NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through NIH. On behalf of our patients, we appreciate your consideration of our views. We look forward to working with you and your staff.

Testimony of Anthony F. (Bud) Rock  
 President and Chief Executive Officer, Association of Science-Technology Centers  
 submitted to the House Appropriations Subcommittee  
 on Labor, Health and Human Services, Education, and Related Agencies  
 April 29, 2015

**Seeking Support for the Following Agencies and Programs in FY 2016:  
 National Institutes of Health – Science Education Partnership Award  
 Institute of Museum and Library Services – Office of Museum Services  
 Department of Education – 21<sup>st</sup> Century Community Learning Centers and Mathematics  
 and Science Partnerships**

Introduction

Chairman Cole, Vice Chair Womack, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to submit written testimony for the record. My name is Anthony (Bud) Rock, and I serve as the President and Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony today addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year (FY) 2016 budgets for four specific offerings at three federal agencies over which your subcommittee has jurisdiction, including: (1) the Science Education Partnership Award (SEPA) program at the National Institutes of Health (NIH), which would receive \$18.5 million under the President's FY 2016 request; the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), which would receive \$33.6 million under the President's FY 2016 request; and the 21<sup>st</sup> Century Community Learning Centers (21<sup>st</sup> CCLC) and Mathematics and Science Partnerships (MSP) programs at the Department of Education (ED), which would receive \$1.15 billion and \$202.7 million, respectively, under the President's FY 2016 request.

Our Request

On behalf of ASTC and the nearly 400 science centers and museums we represent here in the United States, I urge the Subcommittee to continue its strong support for critical STEM and health education programs within NIH, IMLS, and ED as the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for FY 2016 moves forward. Specifically, I ask you to:

- Provide \$20 million for the SEPA program at NIH (FY 2016 request is \$18.5 million);
- Provide \$38.6 million for the OMS at IMLS (FY 2016 request is \$33.6 million);
- Provide \$1.15 billion for the 21<sup>st</sup> CCLC program (same as FY 2016 request) and \$202.7 million for the MSP program (same as FY 2016 request) at ED; and
- Continue to thoroughly examine any proposals that would seek to consolidate and/or reorganize federal STEM, health, and environmental education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Before providing more detail about ASTC and the science center and museum field, I want to

first offer a brief snapshot of these federal programs and why they are so vital to communities across the country.

#### National Institutes of Health

According to NIH, the goal of the **Science Education Partnership Award** program is to invest in educational activities that assist in workforce development to meet the nation's biomedical, behavioral and clinical research needs. By supporting partnerships between researchers and teachers, schools, and institutions like science centers and museums, the SEPA program provides opportunities for students from underserved communities to consider careers in research, provides teachers with professional development in science- and health-related content and teaching skills, and improves community health literacy through exhibits and programming at science centers and museums.

To cite but one example of the SEPA program's current impact, the Yale Peabody Museum of Natural History in New Haven, Connecticut received support to improve communication between research scientists and the general public through development of middle and high school curriculum resources and via museum exhibits and public forums. Teachers, museum educators and research scientists are cooperating in this endeavor, which is centered at the museum and is drawing on the research resources of the Yale School of Medicine. Three infectious, vector-borne diseases—malaria, leishmaniasis, and dengue—are being used as models to provide teachers with engaging and relevant new ways to address their required state and national science standards.

**The President's FY 2016 budget request includes \$18.5 million—the same amount available for FY 2015—for SEPA. Given the program's impact and importance, I ask the Committee to continue its strong support by providing \$20 million for SEPA for FY 2016.**

#### Institute of Museum and Library Services

IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. The agency's **Office of Museum Services** offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects. Just last fall, IMLS announced new grants for 211 museum projects through the Museums for America and National Leadership Grants for Museums programs. In addition, the Sam Noble Museum in Norman, Oklahoma was awarded a 2014 National Medal for Museum and Library Service, the nation's highest honor given to museums and libraries for their service to the community.

**The President's FY 2016 budget request includes \$33.6 million for the Office of Museum Services at the Institute of Museum and Library Services. ASTC asks the Subcommittee to provide \$38.6 million—the congressionally authorized level of funding—for OMS programs for FY 2016.**

#### Department of Education

For years, the **21<sup>st</sup> Century Community Learning Centers** program has supported the creation of community learning centers that provide academic enrichment opportunities during non

school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21<sup>st</sup> CCLC program helps students meet state and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21<sup>st</sup> CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool. The agency's **Math and Science Partnerships** program was intended to increase the academic achievement of students in mathematics and science by enhancing the content knowledge and teaching skills of classroom teachers—an area in which science centers and museums excel. ASTC members, in partnership with local education agencies and institutions of higher education, have implemented MSP programs, and the Department's proposal to use new resources to strengthen the program and to develop and increase the use of evidence-based practices and provide students with opportunities for authentic STEM experiences in formal and informal settings is welcome.

**The President's FY 2016 budget request for the Department of Education includes \$1.15 billion for the 21<sup>st</sup> Century Community Learning Centers program (the same amount available for the previous fiscal year) and \$202.7 million for the Mathematics and Science Partnerships (\$50 million more than the amount appropriated for FY 2015). I encourage the Subcommittee to continue to support both programs by providing the requested funding levels.**

#### STEM Education Consolidation and Reorganization

With regard to the federal STEM education consolidation plan first released by the Administration for FY 2014 and amended in each of the last two budget requests, I recognize the importance of creating efficiencies within the federal government whenever possible. Nevertheless, I continue to have serious concerns about a proposal that would eliminate effective programs that support informal STEM, health, and environmental learning. Integral federal investments, including the SEPA program itself, have been slated for termination in previous fiscal years. While SEPA now enjoys the support of the Administration, programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration were not as fortunate and are, once again, on the chopping block. I sincerely appreciate the Subcommittee's thoughtful consideration of the harmful effect of the proposed terminations, and ask you to remain steadfast in your support of these programs.

#### About ASTC and Science Centers

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As Members of this Subcommittee know, it is imperative that we spark an interest in STEM fields at

an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned support from NIH, IMLS, and ED, in addition to other federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities.

ASTC now counts 636 members, including 489 operating or developing science centers and museums in 45 countries. Collectively, our institutions garner 95 million visits worldwide each year. Here in the United States alone, our guests—and your constituents—pass through science center doors more than 73 million times to participate in intriguing educational science activities and explorations of scientific phenomena.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94% of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as: 92% offer classes and demonstrations; 90% offer school outreach programs; 76% offer workshops or institutes for teachers; 74% offer programs for home-schoolers; 67% offer programs that target adult audiences; 65% offer curriculum materials; 50% offer after-school programs; 34% offer youth employment programs; and 22% offer citizen science projects.

#### Conclusion

With this in mind, and while I am fully aware of the significant budget challenges that face this Subcommittee, Congress, and the nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential federal support they receive from NIH, IMLS, and ED.

**Again, I respectfully request that you provide \$20 million for the Science Education Partnership Awards program at the National Institutes of Health; \$1.15 billion for the 21<sup>st</sup> Century Community Learning Centers program and \$202.7 million for the Mathematics and Science Partnerships program at the Department of Education; and \$38.6 million for the Office of Museum Services at the Institute of Museum and Library Services. In addition, please continue to closely examine any proposals that would seek to consolidate and/or reorganize federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.**

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

**STATEMENT OF NANCY J. NORTON  
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**REGARDING FISCAL YEAR 2016 APPROPRIATIONS  
FOR THE NATIONAL INSTITUTES OF HEALTH**

**SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,  
HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

**APRIL 29, 2015**

- 1) \$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF \$1 BILLION OVER FY 2015. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**
- 2) CONTINUE FOCUS ON DIGESTIVE DISEASE RESEARCH AND EDUCATION AT NIH, INCLUDING, IRRITABLE BOWEL SYNDROME (IBS), FECAL INCONTINENCE GASTROESOPHAGEAL REFLUX DISEASE (GERD) GASTROPARESIS, AND CYCLIC VOMITING SYNDROME (CVS).**

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal and motility disorders (FGIMD) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by FGIMDs, and providing education and support for patients, healthcare providers, and the public. IFFGD also works to advance critical research on FGIMDs in order to develop better treatment options and to eventually find cures.

IFFGD has worked closely with the National Institutes of Health (NIH) on many priorities, and I served on the National Commission on Digestive Diseases (NCDD), which released a long-range plan in 2009, entitled *Opportunities and Challenges in Digestive Diseases Research:*

*Recommendations of the National Commission on Digestive Diseases.*



The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for FGIMDs are close to my heart. My own experiences of suffering from FGIMDs motivated me to establish IFFGD, and I was shocked to discover that despite the high prevalence of FGIMDs among all demographic groups, such a lack of research existed. This translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among the medical community and the public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery. Most FGIMDs have no cure and limited treatment options, so patients face a lifetime of chronic disease management. The costs associated with these diseases range from \$25-\$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

### **IRRITABLE BOWEL SYNDROME (IBS)**

IBS affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. It is a chronic disease that causes abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a “functional disorder,” IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests.

Without a diagnostic test, IBS often goes undiagnosed or misdiagnosed for years. Even after IBS is identified, treatment options are limited and vary from patient to patient. Due to persistent pain and bowel unpredictability, individuals may distance themselves from social events and work.

Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Many people also dismiss their symptoms or attempt to self-medicate with over-the-counter medications. Outreach to physicians and the general public remain critical to overcome these barriers to treatment and assist patients.

## **FECAL INCONTINENCE**

At least 12 million Americans suffer from fecal incontinence. Incontinence crosses all age groups, but is more common among women and the elderly of both sexes. Often it is associated with neurological diseases, cancer treatments, spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, and uterine cancer. Causes of fecal incontinence include: damage to the anal sphincter muscles, damage to the nerves of the anal sphincter muscles or the rectum, loss of storage capacity in the rectum, diarrhea, or pelvic floor dysfunction. People may feel ashamed or humiliated, and most attempt to hide the problem for as long as possible. Some don't want to leave the house in fear they might have an accident in public; they withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly is the primary reason for nursing home admissions, an already significant social and economic burden in our aging population. In 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence through Research: Trial Design, Outcome Measures, and Research Priorities*. IFFGD also collaborated with NIH on the *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults* in 2007.

NIDDK recently launched a Bowel Control Awareness Campaign (BCAC) that provides resources for healthcare providers, information about clinical trials, and advice for individuals suffering from bowel control issues. The BCAC is an important step in reaching out to patients, and we encourage continued support for this campaign. Further research on fecal incontinence is critical to improve patient quality of life and implement the research goals of the NCDD.

## **GASTROESOPHAGEAL REFLUX DISEASE (GERD)**

GERD is a common disorder which results from the back-flow of stomach contents into the esophagus. GERD is often accompanied by chronic heartburn and acid regurgitation, but sometimes the presence of GERD is only revealed when dangerous complications become evident. There are treatment options available, but they are not always effective and may lead to serious side effects. Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year and even more premature infants. GER results from immature upper gastrointestinal motor development. Up to 8% of children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction and may require long-term treatment.

### **GASTROPARESIS**

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly.

Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting, or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, and is present in 30% to 50% of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications. In many patients the cause cannot be found and the disorder is termed idiopathic gastroparesis.

### **CYCLIC VOMITING SYNDROME (CVS)**

CVS is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea and vomiting, accompanied by abdominal pain, prostration, and lethargy, last hours to days. Previously thought to occur

primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in many age groups, including adults. CVS patients often go for years without correct diagnosis. CVS leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Research is needed to help identify at-risk individuals and develop more effective treatment strategies.

## **SUPPORT FOR CRITICAL RESEARCH**

*IFFGD urges Congress to fund the NIH at level of \$32 billion for FY 2016.* Strengthening and preserving our nation's biomedical research enterprise fosters economic growth and supports innovations that enhance the health and well-being of the nation. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to strengthen the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and urges a funding level of \$2.066 billion for FY 2016. Such support would expedite the implementation of recommendations from the NCDD. It is also vital for NIDDK to work with the National Institute of Child Health and Human Development (NICHD) to expand its research on the impact FGIMDs have on pediatric populations. Following years of near level-funding, research has been negatively impacted across all NIH Institutes and Centers. Without additional funding, medical researchers run the risk of losing promising research opportunities that could benefit patients.

We applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposement hold

the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in FY 2016.

Thank you for the opportunity to present these views on behalf of the FGIMD community.



**DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION**

*serving all dystonia-affected persons*

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**STATEMENT OF  
Janet Hieshetter  
Executive Director  
Dystonia Medical Research Foundation**

**ON BEHALF OF  
Dystonia Advocacy Network**

**REGARDING  
Fiscal Year 2016 Appropriations for the National Institutes of Health**

**SUBMITTED TO  
Senate Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related  
Agencies**

**April 3, 2015**

**SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2016:**

- **Provide \$32 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers**
- **Continue to support natural history studies on dystonia, like the *Dystonia Coalition* within the Rare Disease Clinical Research Network (RDCRN) coordinated by the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS)**
- **Expand dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), the National Eye Institute (NEI), and NCATS**

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that

between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful for controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

#### **Dystonia Research at the National Institutes of Health (NIH)**

**The DAN urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, Congress should support NINDS, NCATS, NIDCD, and NEI in conducting and expanding critical research on dystonia.**

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the *Dystonia Coalition*, a partnership between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The *Dystonia Coalition* has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. Studies like the *Coalition* remain a priority for the community and Congress should continue to support these initiatives.

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids.



In summary, the DAN recommends the following for fiscal year 2016:

- Provide \$32 billion for NIH and a proportional increase for its Institutes and Centers
- Support natural history studies on dystonia like the *Dystonia Coalition*, part of the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS
- Expand the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and NCATS

### **The Dystonia Advocacy Network**

The Dystonia Medical Research Foundation submits these comments on behalf of the Dystonia Advocacy Network (DAN), a collaborative network of five patient organizations: the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, the National Spasmodic Torticollis Association, and ST/Dystonia, Inc. The DAN advocates for all persons affected by dystonia and supports a legislative agenda that meets the needs of the dystonia community.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

**Prevent Blindness Written Testimony to the House Appropriations  
Labor, Health and Human Services, Education, and Related Agencies Subcommittee  
Submitted by: Hugh Parry, President & CEO, Prevent Blindness  
April 29, 2015  
Funding Request Overview**

Prevent Blindness respectfully requests that the Subcommittee provide the following allocations in fiscal year (FY) 2016 to help promote eye health and prevent eye disease and vision loss:

- Provide at least \$1,000,000 to strengthen the Vision Health Initiative (visual screening education) at the Centers for Disease Control and Prevention (CDC).
- Provide at least \$3,294,000 to continue the Glaucoma Project at the CDC.
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health.
- Provide at least \$639 million to sustain programs under the Maternal and Child Health (MCH) Block Grant.
- Provide at least \$730 million to the National Eye Institute (NEI).

**Introduction and Overview** Vision-related conditions affect people across the lifespan. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to ten percent of preschool age children, and is a leading cause of impaired health in childhood. Recent research showed that the economic burden of vision loss and eye disorders is \$145 billion each year, nearly \$50 billion of which is federal spending. Alarming, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye

disease and the vision impairment that results is expected to double within the next three decades.”

To curtail the increasing incidence of vision loss in America, and its related economic burden, Prevent Blindness advocates sustained and meaningful federal funding for programs that promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. In a time of significant fiscal constraints, we recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye conditions, and their treatment, through research, to develop the public health systems and infrastructure to disseminate and implement good science and prevention strategies, and to protect children’s vision, millions of Americans face the loss of independence, loss of health, and the loss of their livelihoods, all because of the loss of their vision. Furthermore, an upcoming Institute of Medicine study is expected to make new recommendations to improve the vision and eye health of the population in the coming years; recommendations that would be much more difficult to advance following a decreased investment in these important programs.

**Vision and Eye Health at the CDC: Helping to Save Sight and Save Money**

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to promote eye health and prevent vision loss; improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden; reduce vision and eye health related disparities; and integrate vision health with other public health strategies. Despite severely

constrained financial resources the CDC's Vision Health Initiative (VHI) staff has worked hard in the last year to increase awareness of vision health by partnering with other CDC programs, including the Office of Smoking and Health and the Division of Cancer Prevention and Control. Still, increased funding is absolutely necessary to take the work of the VHI to the next level.

Prevent Blindness requests at least \$1,000,000 in FY 2016 to strengthen vision and eye health efforts of the CDC. This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into state and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy

*Improving Access to Eye Care for those at High Risk for Glaucoma*

An estimated 2.2 million people are affected by glaucoma. A disease of the aging eye, risk for glaucoma increases with age, especially among black, Hispanic/Latinos, and Asians. Once vision is lost to glaucoma, it cannot be restored, but with early diagnosis and appropriate treatment, it is possible to slow disease progression and save the remaining sight. Detection and management of glaucoma are challenged by difficulties in reaching high-risk populations and by the lack of simple, cost-effective screening plans.

Prevent Blindness requests at least \$3,294,000 in FY 2016 to continue the work of the Glaucoma Project to improve glaucoma screening, referral, and treatment. The program is intended to reach those populations experiencing the greatest disparity in access to glaucoma care through an integrated collaboration among private and public organizations.

**Investing in the Vision of Our Nation's Most Valuable Resource – Children** The visual system in children younger than 8 years old is in a critical developmental stage. Unidentified

and untreated vision problems can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Currently, only one in three children receives eye care services before the age of six. Requirements for preventive eye care/vision screenings prior to or during the school years vary broadly from state to state, most with no standardization regarding age-appropriate methods, referral procedures, or follow-up requirement protocols. Inclusion of vision screenings with a comprehensive approach to follow up treatment and data collection will help to change disparities in vision and eye health for our nation's children.

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children. The Center works to achieve its goals in three ways: (1) provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye health care for children; (2) advance state-based performance improvement systems, screening guidelines, and mechanisms for uniform data collection and reporting; and (3) provide technical assistance to states in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

In January 2015, volunteer experts convened by the Center published three articles in the *Journal of Optometry and Vision Science* that provide an evidence-based approach to vision screening in children ages 3 through 5, as well as system-based public health strategies to ensure improved surveillance and program accountability as it relates to children's vision in the United

**Prevent Blindness Written Testimony to the House Appropriations  
Labor, Health and Human Services, Education, and Related Agencies Subcommittee  
Submitted by: Hugh Parry, President & CEO, Prevent Blindness  
April 29, 2015**

States. This guidance encourages a badly needed, more uniform approach to children's vision health systems.

Prevent Blindness also requests at least \$639 million in FY 2016 to sustain programs under the MCH Block Grant. The MCH Block Grant enables states to expand critical health care services to millions of pregnant women, infants and children, including those with special health care needs. In addition to direct services, the MCH Block Grant supports programs, preventive and systems building services needed to promote optimal health – including the National Center for Children's Vision and Eye Health.

**Advance and Expand Vision Research Opportunities** Prevent Blindness calls upon the Subcommittee to provide \$730 million to enable the NEI to pursue its primary "audacious goal" of restoring vision by bolstering its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. By providing additional funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

**Conclusion** On behalf of Prevent Blindness, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding FY 2016 funding for the CDC's vision and eye health efforts, the MCHB's National Center for Children's Vision and Eye Health, and the NEI.

***Prevent Blindness** – the nation's leading non-profit, voluntary organization committed to preventing blindness and preserving sight – maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance and implement policies and programs that prevent blindness and preserve sight. For more information about Prevent Blindness and our federal government relations and public policy efforts, please visit [www.preventblindness.org](http://www.preventblindness.org)*



**CPSD**  
Real lives. Real work.

Collaboration  
to Promote  
Self-Determination

April 29, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

We thank you for your consistent efforts to provide funding for the model comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) programs. We are writing to strongly encourage you to continue to fund this program at the current level in the FY2016 House Labor, HHS Appropriations bill.

The reauthorization of the Higher Education Act in 2008 made an historic commitment to students with intellectual disabilities by establishing new provisions that provided additional access to post-secondary education. One of the most critical provisions made a landmark investment to students with intellectual disabilities by establishing the TPSID programs and National Coordinating Center (NCC).

Since the grant award, the TPSID funding has supported the creation or expansion of programs at 50 colleges and universities serving nearly 2,000 students. These models focus on academic enrichment, socialization, independent living, and employment in order to create, expand or enhance high-quality, inclusive higher education experiences to support positive outcomes for young adults with intellectual disabilities, including paid employment. The comprehensive evaluation system developed by the NCC found that, in just three years, 70% of participating students were involved in career development activities and paid internships. An additional 36% (over 400 students) held paid jobs, of which 89% paid minimum wage or higher, and some students held two or three jobs while they were going to college. These programs are demonstrating that people with I/DD can and will benefit from higher education.

Great strides towards postsecondary education, life in the community and employment are being made through the TPSID programs. However, there are still far too few options available for young people seeking to transition to college and further model development is needed to build on this success. It is essential that the TPSID programs and NCC continue to be funded. On behalf of the CPSD, we strongly urge your support in the FY2016 appropriations bill. If you have any questions, please let Laura Kaloi with CPSD know. She can be reached at her email, [lkaloi@wpllc.net](mailto:lkaloi@wpllc.net).

Sincerely,

Denise Marshall  
Co-Chair  
CPSD Youth in Transition Workgroup  
Council of Parent Attorneys and Advocates

Barbara Trader  
Co-Chair  
CPSD Youth in Transition Workgroup  
TASH

CPSD is a national, family-driven and consumer-led advocacy network of 22 national organizations. These organizations have come together to bring about a significant modernization of the federal system of services and supports for persons with disabilities. We focus on high-impact public policy and systems reform to improve the employment and socio-economic outcomes of citizens with intellectual and developmental disabilities promoting the effective transition of students with developmental disabilities into adulthood by preparing them to obtain optimal outcomes in education, employment, economic advancement, and independent living.

**Testimony of the Association of Public Television Stations (APTS) and  
the Public Broadcasting Service (PBS)  
Prepared for the House Committee on Appropriations, Subcommittee on Labor, Health and  
Human Services, Education and Related Agencies  
the Department of Education  
April 29, 2015**

On behalf of America's 171 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of federal funding for the Ready To Learn program at the Department of Education. We urge the Subcommittee to support level funding of \$25.7 million for the Ready To Learn program in FY 2016.

***The Ready To Learn Program***

Ready To Learn is a competitive grant program that uses the power of public television's on-air, online, mobile, and on-the-ground educational content to build the literacy and STEM skills of children between the ages of two and eight, especially those from low-income families. Through their Ready To Learn grant, CPB and PBS are delivering evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children via broadcast television, the Internet, mobile and other dynamic new technologies. In addition, CPB and PBS are creating new tools like a sophisticated progress tracking system that gives parents the means to measure student progress in real time.

CPB and PBS, in partnership with local stations, have been able to ensure that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources. This is possible by leveraging the trust and community-driven missions of local public television stations. Local stations use their community partnerships to reach underserved communities and families by engaging them on-the-ground, including with mobile learning labs, through Ready To Learn programs and activities. Organizations involved in these successful partnerships include local schools and school agencies, pre-schools, daycare centers, libraries, Boys and Girl Clubs, YMCA's, local housing authorities and others. In addition to



Ready To Learn content being brought to children and families through partnerships, local public stations host events that educate parents and caregivers about the critical role they play in their child's development and academic success and offers tools, resources and advice to maximize both in- and out-of-class learning opportunity.

### ***Local Outreach***

To cite only two illustrative examples of many Ready To Learn successes:

In Oklahoma, OETA offers the Ready to Learn program as a local engagement and outreach program to support the education of Oklahoma's early learners. Specifically, OETA offers one free book per month for children in pre-kindergarten through 3rd grade to help build literacy and Science, Technology, Engineering and Math (STEM) skills in Oklahoma's youngest learners. The Ready To Learn program also supports professional development opportunities for Oklahoma teachers of Pre-K through 3rd grade students in literacy, STEM and instructional technology to help provide educators with additional tools to ensure student success. Also offered are workshops for Oklahoma parents and caregivers that are designed to help empower them with tools and resources to support their child's education. This work is further buttressed through community-based learning events that take learning traditional concepts like literacy and STEM into non-traditional environments with activities led by certified teachers and supported by parents to help strengthen the parent-teacher partnership.

The Connecticut Public Broadcasting Network (CPBN) uses Ready To Learn educational resources to support children, families, educators and caregivers in the community by making the program's educational resources accessible through smart tablets and helping to bridge the digital divide. CPBN efforts have involved numerous community partners including Catholic

Charities for the Brighter Futures Family Centers, Hartford Foundation for Family Giving, and the Boys & Girls Club of Hartford.

### ***Results***

Ready To Learn is rigorously tested and evaluated to assess its impact on children's learning and to ensure that the program continues to offer children the tools they need to succeed in school and in life. Studies show that Ready To Learn has a significant and positive effect on the educational lives of children who use it. Highlights of recent studies show that: use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten<sup>1</sup>; use of Ready To Learn content has been associated with a 29 percent improvement in reading ability in children grades K-2<sup>2</sup>; and parents who used Ready To Learn math resources in the home became considerably more involved in supporting their children's learning outcomes<sup>3</sup>. In combination, Ready To Learn games, activities and videos provide early learners with the critical math and literacy skills needed to succeed in school, and in the process, help level the academic playing field.

### ***An Excellent Investment***

In addition to being research-based and teacher tested, the Ready To Learn program also provides excellent value for our federal dollars. In the last five-year grant round, public broadcasting leveraged an additional \$50 million in non-federal funding to augment the \$73 million investment by the Department of Education for content production. Ready To Learn

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<sup>1</sup> McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to Learn Initiative. Redwood City, CA: WestEd.

<sup>2</sup> Public Broadcasting Service (2012). KBTC Ready To Learn Initiative 2012 Summary Report, pp. 15 + 16

<sup>3</sup> McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to Learn Initiative. Redwood City, CA: WestEd.

exemplifies how the public-private partnership that is public broadcasting can change lives for the better.

### *Conclusion*

The Ready To Learn program symbolizes the mission of public media and is a successful public-private partnership that leverages federal funds to create the most appealing and impactful children's educational content that is supplemented by online and on-the-ground resources. Without Ready To Learn, millions of families would lose access to this incredible high-quality educational content, especially the low-income and underserved households that are a particular focus of this program. We therefore recommend level funding of \$25.7 million for Ready To Learn in fiscal year 2016.



**CPSD**  
*Real lives. Real work.*

Collaboration  
 to Promote  
 Self-Determination

April 29, 2015

Representative Tom Cole  
 Chair, Subcommittee on Labor,  
 Health & Human Services,  
 Education and Related Agencies  
 Committee on Appropriations  
 2467 Rayburn House Office Bldg.  
 Washington, D.C. 20515

Representative Rosa DeLauro  
 Ranking Member, Subcommittee on Labor,  
 Health & Human Services,  
 Education and Related Agencies  
 Committee on Appropriations  
 2413 Rayburn House Office Bldg.  
 Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the Collaboration to Promote Self-Determination (CPSD), we write to urge you to continue appropriations to the Department of Health and Human Services (HHS) for activities promoting community integration for individuals with disabilities.

CPSD is a national, family-driven and consumer-led advocacy network of 22 national organizations. These organizations have come together to bring about a significant modernization of the federal system of services and supports for persons with disabilities. We focus on high-impact public policy and systems reform to improve the employment and socio-economic outcomes of citizens with intellectual and developmental disabilities promoting the effective transition of students with developmental disabilities into adulthood by preparing them to obtain optimal outcomes in education, employment, economic advancement, and independent living.

Many of the activities that have led to successful inclusion of people with disabilities in jobs, living in their own homes and enjoying the benefits of full participation in society have come about because of programs, regulations and policies from Health and Human Services (HHS), the Centers for Medicare and Medicaid Services including and the rules concerning home and community-based services (HCBS), as well as those of HHS component agencies such as the National Council on Disability and the Administration on Intellectual and Developmental Disabilities and its grantees. This also includes implementation and enforcement of the Americans with Disabilities Act and its integration mandate—core to the CPSD mission and supported broadly and passionately by the disability community. These are some of most essential rules and regulations for improving the lives, independence, and well-being of individuals with disabilities.

We were recently alerted to the efforts of an organization that has urged its members to demand language in the Labor, HHS, Education and Related Agencies appropriations bill that would stymie efforts toward integration and independence by prohibiting the use of HHS funds for any activities

that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. This effort is contrary to the strides we have made as a nation and counter to the Supreme Court's landmark decision in *Olmstead v. L.C.*, a critical civil rights decision for the disability community.

Enforcement of the ADA's integration mandate and the *Olmstead* decision are top priorities for CPSD and the greater disability community. *Olmstead* enforcement has been pivotal to the lives of people with disabilities, resulting in a historic level of independence. Thousands of individuals with disabilities have, for the first time, been given the opportunity to live in their own homes and communities, with privacy, dignity, and independence, and they have finally been afforded the opportunity to participate fully in society. Likewise, implementation of new rules in regard to Medicaid-financed home and community-based services are critical to ensuring that disability service systems support the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Additionally, both enforcement of *Olmstead* and implementation of the Medicaid home and community-based services rules do not deny individuals the choice to live in an institution. Rather, under both *Olmstead* and the Medicaid rules, there is now an option for thousands of individuals with disabilities and their families to *opt* for a home and community-based service settings—a choice that was not previously available to many, but is often ideal.

Any implication that individuals with disabilities are being forced to move to a community setting against their wishes undermines the progress made by the community in recent decades- the choice of settings must be preserved through enforcement of HHS rules and *Olmstead*. Prohibiting enforcement of regulations governing HCBS settings through the appropriations process would be a devastating step backward for individuals with intellectual disabilities by stripping them of choice and forcing many back into segregated settings. CPSD urges you to exclude any language to this affect in the appropriations bill.

People with disabilities have made incredible strides toward integration and the opportunity to live, work, and receive services in integrated settings. These life-changing successes must be preserved. We appreciate this opportunity to share our appropriations priorities. Please feel free to contact Kuna Tavalin ([ktavalin@wpllc.net](mailto:ktavalin@wpllc.net)), who would be happy to provide additional information at any time.

Sincerely,

Association of People Supporting Employment First  
 Association of University Centers on Disabilities  
 Autistic Self Advocacy Network  
 Council of Parent Attorneys and Advocates, Inc.  
 National Association of State Directors of Developmental Disabilities Services  
 National Disability Rights Network  
 National Down Syndrome Congress  
 National Down Syndrome Society  
 National Fragile X Foundation  
 National Organization on Disability  
 Service Employees International Union  
 TASH  
 The Autism Society

Susan F. Rzucidlo  
210 Laurel Heights Rd  
Landenberg PA 19350

April 29, 2015

Good Afternoon Honorable Committee Members and the  
Honorable Patrick Meehan,

My name is Susan Rzucidlo, and I live in Chester County Pennsylvania. I am the mother of 4 children, one of who lives with a severe form of autism and a profound intellectual disability. I understand that you are being lobbied from two sides of the disability community, those who believe that everyone must live in the community and those who want to keep the option of segregated residential settings.

As a mom and an advocate I hope that you will take a middle ground approach to this difficult and emotionally charged issue. I believe that what is truly needed is a full continuum of services provided in the places where the individual wants them provided. These services must be truly tailored to meet the needs of each individual. The push that everyone must be included is counterproductive to a quality lifestyle. Just being in a house in the middle of a neighborhood doesn't mean that you have friends who are not paid or

that you have meaningful relationships, community connections or enjoyable activities in the neighborhood.

My other adult children who do not have disabilities can live in a city or on a farm. They can live alone or with others, with all men, all women or a mix. They can choose to live in a heterogeneous community or a homogeneous community. They have the freedom to choose the living arrangement that suits them as long as it meets zoning and safety regulations. My son who carries a significant disability diagnosis is directed to live in certain settings that some professional has determined is best for him regardless of his needs or desires. Often times professionals who say that the person who has a disability needs to be respected and their voice needs to be heard, only truly listen to the individuals desires if they choose the decision that the professional prefers, otherwise they decide that the individual just doesn't have the right information to make an "informed" decision. And really, wasn't it blindly following professional's advice what got us into this mess with bad institutions? Professionals told families to place their children in institutions and forget them. Professionals said that parents were not capable to take care of their own children. Much like the same statements being made now against families who want to have a voice and a say in the

decisions for their children.

My son Ben was diagnosed in 1995 and I was told to place him because it was unfair to my other children to have to live with him. I chose not to do that. My son was fully included for his educational career. He was the first severe student ever to stay in our district with his typical peers. That being said, I cheer the Arc in Florida has created a community that is focused on providing a quality lifestyle that is very similar to any over-55 community that can be found in any state in the union. Why is it acceptable for me to live in that type of community but not acceptable for my son to live in a community that offers the supports that he enjoys and needs while working to provide community inclusion and activities? Why doesn't he get to have a choice?

I implore you to create language that directs the states to truly listen to the individual and their guardians and allow for the creation of living situations that are safe, enjoyable, and nurturing to the residents. Allow families to have a voice and allow the voice of the individual to be heard and respected. Please don't push the pendulum so far in the other direction that we over compensate and a generation from now we have to correct course again.



Let's find the right path this time and move forward with respect for the individual and their guardians. Let's make sure that each individual has the right to choose where he or she lives and with whom they live.

Thank you for your time and consideration

Respectfully,

Susan F. Rzucidlo

Ben's mom.

**Testimony of the Association of Public Television Stations (APTS) and  
the Public Broadcasting Service (PBS)  
Prepared for the House Committee on Appropriations, Subcommittee on Labor, Health and  
Human Services, Education and Related Agencies  
Regarding funding for the Corporation for Public Broadcasting  
April 29, 2015**

On behalf of America's 171 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of federal funding for local public television stations and PBS. We urge the Subcommittee to support level funding of \$445 million in two-year advance funding for the Corporation for Public Broadcasting (CPB) in FY 2018 and \$40 million for the Public Television Interconnection System in FY 2016.

**Corporation for Public Broadcasting: \$445 million (FY 2018), two-year advance funded**

Local stations and PBS are committed to serving communities throughout the United States in the areas of education, public safety, and civic leadership through broadcast, online, mobile technologies and on the ground outreach. Federal funding for CPB, of which over 70% goes directly to stations, makes these services possible and is deserving of continued support. Based on a 2011 bipartisan Hart Research Associates/American Viewpoint poll, the overwhelming majority of Americans agree and support federal funding. Additionally, annual polls show that Americans consider PBS to be an excellent value for tax dollars relative to other services the government funds, behind only military defense.

***Education***

Public television serves as America's largest classroom, meeting local communities' lifelong education needs by providing the highest quality educational content and resources on multiple media platforms and in-person. Public television's exceptional content is available to nearly every household in America and has reached more than 90 million pre-school age children. PBS and local stations have created PBS LearningMedia, an online portal where more than 1.6 million K-12 educators and 30 million students -- including 39,000 homeschoolers -- can access more than 100,000 standards-based interactive digital learning objects created from public

television content, as well as material from the Library of Congress, the National Archives and other treasured national resources. Local stations also operate virtual high schools that bring high-quality instruction to remote areas.

Through the American Graduate Initiative, CPB and public media stations are working to confront the dropout crisis in America's high schools by providing resources and services to communities to lower the drop-out rate in their schools. In addition, by operating the most comprehensive non-profit GED programs in the country, public television stations have helped hundreds of thousands of individuals get their high-school equivalency certificate. Public television stations have also made it a top priority to help retrain the American workforce, including veterans, by providing digital learning opportunities for those looking for training, licensing, and more.

### ***Partners in Public Safety***

Public broadcasting stations throughout the country are leading innovators and irreplaceable partners to local public safety officers. Our system provides the redundant path for the Warning Alert and Response Network enacted by Congress in 2006, in which local stations use their broadcast equipment to help send emergency alert text messages to cell phone subscribers — reaching citizens wherever they are. This digital infrastructure also enables stations to provide state and local officials with critical community emergency alert, public safety, first responder and homeland security services and information during emergencies. Stations are increasingly partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways, with many serving as their states' Emergency Alert Service (EAS) hub for weather and AMBER alerts.

### ***Supporting Civic Leadership***

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their states and their country. Local public television stations often serve as the state-level “C-SPAN,” airing state government proceedings. Local stations also provide more public affairs programming, local history, arts and culture, candidate debates, agricultural news, and citizenship information of all kinds than anyone else.

### ***Public Broadcasting is a Smart Investment***

All of this is made possible by the federal funding to CPB that amounts to about \$1.35 per year, per American. For small and rural stations, whose local fundraising is more difficult due to a smaller and often economically strained population base, federal funding can represent 30-50 percent of their total budgets. It is also more costly to serve rural areas due to challenging topography and distances between communities, despite sometimes serving as the only local broadcaster. For all stations, federal funding provides the critical seed money to build additional support from state legislatures, foundations, corporations, and “viewers like you.”

Thus, for every dollar in federal funding, local stations raise six dollars in non-federal funding, creating a strong public-private partnership and an impressive 6 to 1 amplification of the federal investment while supporting approximately 20,000 jobs across America.

### ***Two-Year Advance Funding***

The longstanding practice of two-year advance funding, proposed by President Ford and embraced by Congress in 1976, enables the leveraging of funds to ensure a successful public-private partnership, provides stations with the necessary lead time to plan in-depth programming and accompanying educational materials, and establishes a firewall insulating programming decisions from political interference – all of which contribute to unprecedented levels of public

trust. For the 12<sup>th</sup> consecutive year, in 2015, the American people have again ranked PBS #1 in trust ahead of other private and public institutions in an independent poll.

Local stations leverage the two-year advance funding to raise state, local and private funds, ensuring the continuation of this strong public-private partnership. Advance funding also benefits the partnership between states and stations since many states operate on two-year budget cycles. Finally, the two-year advance funding mechanism makes it possible for producers like Ken Burns to create the in-depth, multi-hour series like the forthcoming histories of the Vietnam War and of country music with all the scholarly influence and educational components that make such programming so valuable to the American people.

**Public Television Interconnection System: \$40 million in FY 2016**

The public television interconnection system is the infrastructure that connects PBS and national, regional and independent producers to every local station around the country. The interconnection system is essential to bringing public television's programming to every American household, no matter how rural or remote. The interconnection system is also critical for public safety, providing key redundancy for presidential alerts and warnings, and ensuring that cellular customers can receive geo-targeted emergency alerts and warnings.

Congress recognized the need for interconnection when it created CPB and authorized it to “assist in the establishment and development of one or more interconnection systems” in the Public Broadcasting Act of 1967. As technology has advanced, public television has worked to make the interconnection system more efficient while increasing the timely access to programming for every station. Congress has always provided federal funding for periodic upgrades to and replacement of the interconnection system when necessary. The last two rounds of interconnection funding were provided by Congress in FY 1991–1993 and FY 2004–2007.

### ***The Next Interconnection System***

Current interconnection satellite leases, support contracts, and existing financing expire on September 30, 2016. CPB and the public television system are committed to ensuring that the next interconnection system efficiently supports our universal service and public service commitments, while taking advantage of technological advances. In the proposed PBS designed system, the majority of content would be distributed through leased fiber-optic data lines and would allow stations to connect and collaborate with one another, producers, and PBS. Minimal satellite capacity would be retained for redundancy. For FY 2016, \$40 million is necessary for the down payment on a multi-year \$197 million request to replace the interconnection system. It is critical that Congress provide this funding in FY 2016 to ensure that implementation of the next interconnection system can begin in time to avoid any interruption of service.

### **Conclusion**

Americans across the political spectrum rely on public broadcasting on television, radio, online, and in the classroom – because we provide essential education, public safety, and informed citizenry services that are not available anywhere else. None of this would be possible without the federal investment. A 2007 GAO report concluded that federally appropriated support of public television stations is an irreplaceable source of revenue for public broadcasting, and a 2012 study conducted by an independent third party for CPB came to the same conclusion. For all of these reasons we request that Congress continue its commitment to the highly successful, critically important public-private partnership that is public broadcasting by providing level funding of \$445 million in FY 2018 for the two-year advance of the Corporation for Public Broadcasting and \$40 million in FY 2016 for the Public Television Interconnection System.

# TRANSPLANT ROUNDTABLE

TESTIMONY  
FOR THE WRITTEN RECORD  
BEFORE THE

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES

ON FISCAL YEAR 2016 FUNDING FOR THE

## **DIVISION OF TRANSPLANTATION**

HEALTH RESOURCES AND SERVICES ADMINISTRATION  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

BY THE UNDERSIGNED ORGANIZATIONS OF THE TRANSPLANT ROUNDTABLE

Alliance for Paired Donation  
American Association of Kidney Patients  
American Association for the Study of Liver Diseases  
American Society of Nephrology  
American Society of Pediatric Nephrology  
American Society of Transplantation  
American Society of Transplant Surgeons  
American Transplant Foundation  
Association of Organ Procurement Organizations  
Coalition to Promote Living Kidney Donation  
Dialysis Patient Citizens  
Donate Life America  
Eye Bank Association of America  
NATCO, The Organization for Transplant Professionals  
National Kidney Foundation  
National Kidney Registry  
Renal Physicians Association  
Texas Transplant Society  
Transplant Recipients International Organization  
United Network for Organ Sharing  
WaitList Zero

APRIL 29, 2015

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the Transplant Roundtable, a coalition of organizations representing organ transplant patients and professionals, we offer our strong support for increased federal funding in fiscal year 2016 for the organ donation and transplantation programs administered by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA). We applaud you and this Subcommittee for many years of unwavering commitment to these programs and ask again for your assistance. While we recognize the serious challenges regarding the federal budget and annual appropriations, it is critical that the federal government retain its strong commitment to the Division of Transplantation ("DoT"). The President proposed a FY 2016 appropriation of \$23,549,000, the same level as the FY 2015 appropriated amount. *Given the persistent need for donor organs and the many important programs administered and supported by the Division of Transplantation, we ask that you appropriate an increase of \$3,000,000 for fiscal year 2016 to bring the budget to \$26,549,000. This appropriation level would finally bring the DoT budget beyond the historical high of \$25 million achieved back in FY 2002.*

The DoT serves a unique and irreplaceable function in helping to facilitate organ donation and transplantation, serving the needs of critically ill Americans in need of an organ transplant to survive. Programs supported and administered by the DoT save lives and improve the quality of life of thousands of Americans. DoT provides oversight and funding for the nation's organ procurement, allocation, and transplantation system through the Organ Procurement and Transplantation Network (OPTN). It coordinates all organ and tissue donation activities and funds donation research.



Further, through the National Living Donor Assistance Center (NLDAC), it provides funding for travel and subsistence expenses of living donors whose low incomes may otherwise prohibit them from donating. The NLDAC program has helped facilitate organ transplantation for over 2,500 recipients since its inception, saving lives while saving the Medicare program over \$60 million in dialysis services that were no longer necessary due to successful transplantation. These and other programs funded through DoT are very worthy of additional federal investment as they produce a major return on this investment, year after year.

According to the Organ Procurement and Transplant Network (OPTN), there were 29,532 organ transplants performed from 14,412 donors in 2014. One organ donor can provide enough organs to save up to eight lives. And yet, demand for donor organs continues to outstrip supply by a wide, persistent margin. Every ten minutes a person is added to the transplant waiting list and 21 individuals die each day awaiting a donor organ, according to the OPTN. According to the United Network of Organ Sharing (UNOS), as of March 2015, the national patient waiting list for organ transplants contained more than 78,000 “active” patients and over 123,000 total patients awaiting donor organs. “Active” status refers to patients who are medically ready and able to receive a transplant when one becomes available.

Congressional, agency and private sector support has resulted in transplantation that has saved and enhanced the lives of well more than 600,000 people in the United States, helped to greatly reduce the number of deaths on the waiting list, and generated substantial savings to the Medicare program through foregone need for dialysis. As a country, we do very well in facilitating and providing these life-saving services, but we need sustained federal commitment and resources to continue to meet the relentless, continuing need for donor organs.

Your leadership has been exemplary over many years on transplantation and organ donation activities. On behalf of transplant patients and their families, we ask that you to

continue your leadership on federal organ donation and transplantation programs by increasing federal funding for the Division of Transplantation under the Health Resources and Services Administration.

Thank you for the opportunity to submit this testimony for the written record.



# NACDD

National Association of Councils  
on Developmental Disabilities

Testimony Submitted By:

*Cindy Smith, MS, CAS, JD*

*Director of Public Policy*

*National Association of Councils on Developmental Disabilities*

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*202-506-5813*

*[csmith@nacdd.org](mailto:csmith@nacdd.org)*

Dear Chairman Cole and Ranking Member DeLauro:

The National Association of Councils on Developmental Disabilities (NACDD) is the national membership organization for the Councils on Developmental Disabilities (DD Councils) appointed by Governors, and located in every state and territory. For over half a century, the DD Councils have worked with policymakers and community partners, including people with developmental disabilities and their families, to achieve systemic changes through the creation of outstanding programs and services as mandated in the Developmental Disabilities and Bill of Rights Act (DD Act).<sup>1</sup> The central purpose of the DD Act is to “is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs.”<sup>2</sup> Because of the DD Act, and other federal statutes, people with developmental disabilities have the opportunity live, work, and recreate in their communities as equal and full members of society. NACDD respectfully

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<sup>1</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. 15001 et. seq.

<sup>2</sup> 42 U.S.C. 15001(b)

requests that Congress appropriate \$76 million for the DD Councils in FY 2016 within the Administration for Community Living account contained in the Labor-HHS-Education appropriations bill, and that no language be included in the Committee report limiting the DD Councils from carrying out their statutory mandates included in the DD Act.

Title II of the Americans with Disabilities Act (ADA) states that “...no qualified individual with a disability shall, by reason of such disability, be excluded from participation in, or be denied benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”<sup>3</sup> In what is commonly referred to as the integration mandate, the implementing regulations defines discrimination as public entities not administering “services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>4</sup> In 1999, the U.S. Supreme Court issued its decision in *Olmstead v. L.C.*, which interpreted the integration mandate, and stated the “proper construction of the antidiscrimination provision of Title II of the ADA may require placement of persons with disabilities in community settings rather than in institutions when treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities.”<sup>5</sup> The *Olmstead* decision is frequently considered the *Brown v. Board of Education* for the disability community.

Enforcement of the ADA’s integration mandate and the decision in *Olmstead* is a key priority for the disability community. Since the decision in *Olmstead*, the federal government,

<sup>3</sup> Americans with Disabilities Act of 1990, 42 U.S.C. 12132.

<sup>4</sup> 28 C.F.R. Sec. 35.130(d).

<sup>5</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1999), available at <http://www.clearinghouse.net/chDocs/public/PB-GA-0001-0004.pdf>

and other stakeholders including the DD Councils have worked to re-balance the service delivery system. The Olmstead decision has brought some of the most significant improvements to the lives of people with disabilities in decades. Many individuals with disabilities have, for the first time, been given opportunities to live in their own homes and communities, with privacy, dignity, and independence. They have been able to participate as full and equal members of their natural communities. The DD Councils have helped in realizing this opportunity.

For example, the Georgia DD Council in 2010 launched “Real Communities” which is a cutting edge initiative launched statewide to partner with local groups working to build more just communities. It is a thoughtful, action learning approach that equips community members, people at the local level to work together toward common goals to improve their own community using person-centered supports, community-centered connections, and persistent and reflective learning. Purposefully involving people with and without developmental disabilities in collaborative projects is pivotal to the framework of Real Communities. For more information, see <http://www.gcdd.org/real-communities/about-rc.html#sthash.dnc7cTm8.dpuf>.

Employment is a key component of community living, and over 26 DD Councils have been leaders in innovative Project Search programs that immerse students with DD in their final years of special education in real workplace environments. The projects teach independence and work skills that meet their and their employers’ needs. Very high percentages of Project Search graduates go on to hold regular, paid, integrated jobs with the employers.

In January 2014, the Centers for Medicare & Medicaid Services (CMS) released final regulations regarding the settings of Home and Community-Based Services (HCBS).<sup>6</sup> The rule applies to Medicaid-funded programs that are designated HCBS including the 1915(c) waivers (generally known as “waiver programs”), 1915(i) state plan HCBS, 1915(k) Community First Choice state plan option, and 1115 demonstration waivers that include HCBS. The rule does not apply to services that are not funded by Medicaid (such as state-funded or privately-funded services) or to services funded under non-HCBS Medicaid authorities (such as institutional services or general state plan services). The final rule provides states up to 5 years to implement the new requirements set forth through a transition process that supports continuity of services for individuals who utilize Medicaid and attempts to minimize disruption of services to individuals even as changes to services are made. NACDD is fully supportive of the rule as a needed step forward to ensure people with disabilities can fully participate in their natural communities when receiving supports through HCBS funded programs.

NACDD is aware that at least one organization has requested language in the Labor-HHS-Education appropriations bill that would prohibit the use of HHS funds, including those appropriated to the DD Councils, from engaging in activities that might limit the opportunities for persons with disabilities to participate in their natural communities. The perspectives of one organization through testimony or surveys of their membership should not be considered to be representative of the perspective of other national and state organizations focused on

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<sup>6</sup> Medicaid Program; State Plan Home and Community-Based Services, 5- Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers , 79 Fed. Reg. 2948 (Jan. 16, 2014), available at <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>

protecting and enhancing the civil rights of persons with disabilities as included in the ADA and DD Act. A request to include any language through the appropriations process in the Committee report regarding the statutory obligations of the DD Councils is unnecessary, and not supported by NACDD.

In summary, enforcement of the ADA, Olmstead and the HCBS Rule offer individuals and their families the option of choosing to live in the community, and engage in all aspects of community life such as participation in education, employment and recreation —an option that has been unavailable for far too long to too many people with intellectual and developmental disabilities. The DD Councils have played a central role in ensuring access to all aspects of community living, and should receive additional funding to continue their work to ensure people with developmental disabilities can realize these opportunities. No language should be included in the Committee report that would restrict the DD Councils from working to meet their statutory obligations under the DD Act.



**Testimony of the Nursing Community**  
**Prepared for the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies**

**U.S. Department of Health and Human Services**  
**Health Resources and Services Administration**

**National Institutes of Health**

**April 29, 2015**

*Submitted by Suzanne Miyamoto, Convener of the Nursing Community*

The Nursing Community is a coalition comprised of 61 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare issues surrounding education, research, and practice. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents over one million Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs-including certified nurse-midwives (CNMs), nurse practitioners (NPs), clinical nurse specialists (CNSs), and certified registered nurse anesthetists (CRNAs)), nurse executives, nursing students, faculty, and researchers. For FY 2016, our organizations respectfully request \$244 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the *Public Health Service Act* [42 U.S.C. 296 et seq.]) and \$150 million for the National Institute of Nursing Research (NINR), one of the centers and institutes within the National Institutes of Health (NIH).

**Nurses are Essential to Ensuring Access to High-Quality Care**

As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. RNs comprise the largest group of health professionals with approximately over three million licensed providers in the country. The



reach of their care is vast: they offer essential patient care in a variety of settings, including hospitals, long-term care facilities, community centers, state and local health departments, schools, workplaces, and patient homes.

Factors including an aging nursing workforce, an aging Baby Boomer population, and growth in newly-insured individuals are driving the demand for nursing services. Additionally, as our nation's healthcare system transforms and more services are provided outside of hospital walls, nurses must be educated for these challenges and opportunities. Therefore, the recruitment and retention of RNs and APRNs to underserved areas are a national priority. Moreover, increasing the number of nursing professionals with advanced education to serve in this capacity is of critical importance.

The U.S. Bureau of Labor Statistics (BLS) projects that employment of CRNAs, CNMs, and NPs is expected to grow 31% between 2012 and 2022.<sup>1</sup> A constant focus must be placed on education to ensure a stable workforce, particularly in geographic regions that will continue to experience health provider shortages in the coming years. A significant investment must be made in the education of new nurses to provide the nation with the services it demands.

### **Title VIII Nursing Workforce Development Programs: Ensuring a Pipeline of Highly-Educated Nurses to Serve Across the Nation**

For over 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped to build the supply and distribution of qualified nurses to meet our nation's healthcare needs. Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate

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<sup>1</sup> U.S. Bureau of Labor Statistics. (2014). Occupational Outlook Handbook. *Registered Nurses*. Retrieved from: <http://www.bls.gov/ooh/healthcare/registered-nurses.htm>.

nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met.

Title VIII programs target specific aspects of America's nursing workforce and patient populations that require federal support in order to ensure efficient and effective delivery of healthcare services. For example, in academic year 2013-2014, the Nurse Education, Practice, Quality, and Retention (NEPQR) program supported 9,448 students. Among them, 45 were recipients of the innovative NEPQR Veterans' Bachelor of Science in Nursing program, which assists America's servicemen and women in pursuit of a nursing career. In addition, 900 health professions students received clinical training at NEPQR-supported Nurse-Managed Health Clinics, of which 94% were located in medically underserved areas; 54% served as primary care settings for the community, and 40% of which served veteran populations and their families.<sup>2</sup>

As noted, the BLS projects a high need for APRNs due to increasing patient care demands. The Advanced Nursing Education (ANE) grants program supported 10,504 students in academic year 2013-2014. ANE grants help prepare NPs, CNSs, CNMs, CRNAs, nurse educators, administrators, public health nurses, and other nurses requiring a graduate degree. The settings in which these students were educated reflect the national effort to immerse providers into delivery settings where they are most needed. During this same year, ANE grantees partnered with 5,100 clinical training sites, and 46% were located in underserved areas and 40% were in primary care settings. Students are afforded the opportunity to serve the unique needs of these communities, thus provided care for regions of our nation that struggle to recruit and retain highly-educated clinicians. Federal dollars

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<sup>2</sup> U.S. Department of Health and Human Services. (2015). Health Resources and Services Administration Fiscal year 2016 Justification of Estimates for Appropriations Committees. Retrieved from: <http://hhsa.gov/about/budget/budgetjustification2016.pdf>.

allocated to Title VIII programs are a lifeline to the nursing profession that yields a high return on investment for communities across the country. *The Nursing Community respectfully requests \$244 million for the Nursing Workforce Development programs in FY 2016.*

### **National Institute of Nursing Research: Foundation for Evidence-Based Care**

The care that RNs and APRNs provide must be rooted in evidence. As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. Our country must look toward the prevention aspect of health care as the vehicle for saving our system from further financial burden, and the work of NINR embraces this endeavor through research related to care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR addresses these challenges through its Strategic Plan, which includes the themes of: symptom science for patients with chronic illness and pain; wellness to prevent illness across conditions, settings, and the lifespan; patient self-management to improve quality of life; and end-of-life and palliative care science.<sup>3</sup>

In addition, NINR recognizes the need for improving global health and promotes research to reduce communicable diseases such as HIV, and improve public health and wellness such as maternal-newborn care. Moreover, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. Training

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<sup>3</sup> National Institutes of Health. National Institute of Nursing Research. *Implementing NINR's Strategic Plan: Key Themes*. Retrieved from: [http://www.ninr.nih.gov/aboutninr/keythemes#NRVbGWZ\\_SSL](http://www.ninr.nih.gov/aboutninr/keythemes#NRVbGWZ_SSL).

programs at NINR develop future nurse researchers, many of whom also serve as faculty in our nation's nursing schools.

***The Nursing Community respectfully requests \$150 million for the NINR in FY 2016.*** The

Ad Hoc Group for Medical Research requests at least \$32 billion for NIH in 2016, and the request level of \$150 million for NINR denotes the same percentage increase for NIH applied to NINR.

### **Members of the Nursing Community Submitting this Testimony**

Academy of Medical-Surgical Nurses	Hospice and Palliative Nurses Association
American Academy of Ambulatory Care Nursing	Infusion Nurses Society
American Academy of Nursing	International Association of Forensic Nurses
American Assembly for Men in Nursing	International Society of Psychiatric-Mental Health Nurses
American Association of Colleges of Nursing	National American Arab Nurses Association
American Association of Critical-Care Nurses	National Association of Clinical Nurse Specialists
American Association of Heart Failure Nurses	National Association of Neonatal Nurse Practitioners
American Association of Nurse Anesthetists	National Association of Neonatal Nurses
American Association of Nurse Assessment Coordination	National Association of Nurse Practitioners in Women's Health
American Association of Nurse Practitioners	National Association of Pediatric Nurse Practitioners
American Association of Occupational Health Nurses	National Black Nurses Association
American College of Nurse-Midwives	National Council of State Boards of Nursing
American Nephrology Nurses' Association	National Forum of State Nursing Workforce Centers
American Nurses Association	National Gerontological Nursing Association
American Organization of Nurse Executives	National Nursing Centers Consortium
American Pediatric Surgical Nurses Association	National Organization of Nurse Practitioner Faculties
American Psychiatric Nurses Association	Nurses Organization of Veterans Affairs
American Society for Pain Management Nursing	Oncology Nursing Society
American Society of PeriAnesthesia Nurses	Organization for Associate Degree Nursing
Association for Radiologic and Imaging Nursing	
Association of Community Health Nursing Educators	
Association of Nurses in AIDS Care	
Association of periOperative Registered Nurses	
Association of Public Health Nurses	
Association of Rehabilitation Nurses	
Association of Women's Health, Obstetric and Neonatal Nurses	
Commissioned Officers Association of the U.S. Public Health Service	
Dermatology Nurses' Association	
Developmental Disabilities Nurses Association	
Emergency Nurses Association	
Gerontological Advanced Practice Nurses Association	



**Testimony of the American Association of Colleges of Nursing  
Prepared for the U.S. House Appropriations Subcommittee on Labor, Health and Human  
Services, and Education, and Related Agencies**

**U.S. Department of Health and Human Services  
Health Resources and Services Administration (HRSA)**

**National Institutes of Health (NIH)**

**April 29, 2015**

Submitted by Suzanne Miyamoto, PhD, RN, Senior Director of Government Affairs  
and Health Policy, American Association of Colleges of Nursing

As the national voice for baccalaureate and graduate nursing education, the American Association of Colleges of Nursing (AACN) represents over 760 schools of nursing that educate over 450,000 students and employ more than 17,000 faculty members. Collectively, these institutions prepare approximately half of our nation's Registered Nurses (RNs) and all nurse faculty members, Advanced Practice Registered Nurses (APRNs), and nurse scientists.

AACN respectfully requests that the subcommittee invests in America's health by providing **\$244 million for HRSA's Nursing Workforce Development programs** (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]) and **\$150 million for the National Institute of Nursing Research (NINR)** within the NIH in Fiscal Year (FY) 2016. The Ad Hoc Group for Medical Research requests at least \$32 billion for NIH in FY 2016, and the request level of \$150 million for NINR denotes the same percentage increase for NIH applied to NINR. These levels will ensure that our nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

### **The Role of Nurses in Our Healthcare System**

As integral members of the healthcare team, and as the largest sector of the workforce with over three million licensed providers, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. Nurses serve in a multitude of settings, including hospitals, long-term care facilities, community centers, local and state health departments, schools, workplaces, and patient homes. RNs and APRNs treat and educate patients across the entire life span and ensure individuals follow through with care plans for optimal health outcomes.

In light of the national effort to meet increasing demands for care, our healthcare system will continue to transform. Innovative delivery models that promote efficiency and effectiveness require a team-based approach. AACN believes the demand for high-quality health services will only be achieved through collaboration with other health professions to provide safe, cost-effective, and patient-centered care. In order to do so, it is imperative that individuals seeking to enter the nursing profession are educated in a system that upholds these values. Investments are essential to ensure that a robust workforce of RNs and APRNs are available to provide the care that Americans need now and in the years to come.

### **How Title VIII Programs Serve the Public Today and in the Future**

For over five decades, the Nursing Workforce Development programs have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. The programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support to educate nurses to practice in rural and medically underserved communities.

Title VIII programs are essential to ensuring that the demand for nursing care is met by supporting future practicing nurses and the faculty who educate them. Moreover, the goals of these programs align with the Institute of Medicine's report, *Future of Nursing: Leading Change, Advancing Health*, which calls for nurses to "achieve higher levels of education and training through an improved education system that promotes seamless academic progression."<sup>1</sup>

Title VIII programs address specific aspects of the nursing pipeline and patient populations experiencing high need, such as primary care, diversity in the workforce, and the aging population. Our healthcare system is experiencing a demand for APRNs (which include nurse practitioners (NPs), certified registered nurse anesthetists (CRNAs), certified nurse-midwives (CNMs), and clinical nurse specialists), all of which require advanced degrees. According to the U.S. Bureau of Labor Statistics, the projected employment of NPs, CRNAs, and CNMs is expected to grow 31% between years 2012-2022.<sup>2</sup> APRNs are a real solution to the challenge of employing high-quality providers in underserved areas. Title VIII programs, such as the Advanced Education Nursing Traineeship (AENT) and Nurse Anesthetist Traineeship (NAT), facilitate this process by providing financial assistance to students pursuing an advanced practice degree. In academic year 2013-2014, AENT and NAT programs supported 5,650 students. Of these recipients, 56% received training in medically underserved areas, and 48% received training in primary care settings. Furthermore, 40% of trainees were from minority or disadvantaged backgrounds.<sup>3</sup>

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<sup>1</sup> Institute of Medicine. (2010). *Future of Nursing: Leading Change, Advancing Health Report Recommendations*. Retrieved from: <http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health/Recommendations.aspx>.

<sup>2</sup> U.S. Bureau of Labor Statistics. (2014). *Occupational Outlook Handbook: Nurse Anesthetists, Nurse Midwives, and Nurse Practitioners*. Retrieved from: <http://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm>.

<sup>3</sup> U.S. Department of Health and Human Services. (2015). *Health Resources and Services Administration Fiscal Year 2016 Justification of Estimates for Appropriations Committees*. Retrieved from: <http://hrsa.gov/about/budget/budgetjustification2016.pdf>.

According to the U.S. Census Bureau, individuals from ethnic and racial minority groups account for more than one-third of the U.S. population.<sup>4</sup> With projections pointing to minority populations becoming the majority by 2043<sup>4</sup>, professional nurses must demonstrate a sensitivity to and understanding of a variety of cultures to provide high-quality care across settings. The Title VIII Workforce Diversity Grants program specifically targets groups under-represented in nursing by awarding grants and contract opportunities to schools of nursing, nurse-managed health centers, academic health centers, state or local governments, and nonprofit entities looking to increase access to nursing education for these students. In academic year 2013-2014, the program supported 16,997 students and aspiring students, partnering with over 1,000 clinical training sites—of which 54% were located in medically underserved areas.<sup>3</sup>

Another equally important component of education, practice, and patient needs that Title VIII programs address is supporting education of students who will care for America's aging population. In 2011, the oldest cohort of the Baby Boomer population, nearly 80 million Americans, turned 65, and approximately 10,000 Baby Boomers will reach age 65 each day through 2030.<sup>5</sup> The Title VIII Comprehensive Geriatric Education program supports students who, upon graduation, will provide care to elderly Americans. More specifically, the program provides traineeships for individuals pursuing advanced education nursing degrees in geriatric nursing, long-term care, and gero-psychiatric nursing. Additionally, the program awards grants to train faculty in geriatrics. **AACN respectfully requests \$244 million for the Title VIII Nursing Workforce Development programs in FY 2016.**

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<sup>4</sup> U.S. Census Bureau. (2012). *U.S. Census Bureau Projections Show a Slower Growing, Older, More Diverse Nation a Half-Century from Now*. Accessed June 26, 2014 from: [www.census.gov/newsroom/releases/archives/population/cb12-243.html](http://www.census.gov/newsroom/releases/archives/population/cb12-243.html)

<sup>5</sup> Pew Research Center. (2010). *Baby Boomers Retire*. Retrieved from: <http://www.pewresearch.org/daily-number/baby-boomers-retire/>.



### **National Institute of Nursing Research: Improving Care through Evidence**

As one of the 27 Institutes and Centers at the NIH, NINR develops knowledge to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and enhance end-of-life and palliative care.<sup>6</sup> Broadly speaking, these priorities focus on reducing disease and promoting health and wellness across the entire lifespan. Nurse scientists, often working collaboratively with other health professions, generate the evidence that drives practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. In addition, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. According to 2014-2015 AACN data, there are 5,290 doctoral students pursuing their PhD within AACN member schools, many of whom will also serve as faculty in our nation's nursing schools.<sup>7</sup> NINR training programs, such as the Career Transitions Award and Graduate Partnerships Program, are critical to supporting this cohort of students. These future nurse scientists will help discover new and effective care technologies and methods to improve patient wellness. **AACN respectfully requests \$150 million for the NINR in FY 2016.**

Thank you for considering AACN's request in FY 2016. If you have any questions, or if AACN can be of assistance, please contact AACN's Senior Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto, at [Smiyamoto@aacn.nche.edu](mailto:Smiyamoto@aacn.nche.edu) or 202-463-6930, ext. 247.

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<sup>6</sup> National Institute of Nursing Research. (2012). *FAQ*. Retrieved from: <https://www.nih.gov/site-structure/fq#nursingresearch>.

<sup>7</sup> American Association of Colleges of Nursing. (2015). *2014-2015 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing*. Washington, DC.



Pediatric Congenital  
Heart Association

## **FY2016 WRITTEN TESTIMONY FOR THE RECORD**

April 29, 2015

House Committee On Appropriations  
Subcommittee On Labor, Health And Human Services, Education And Related Agencies

RE: FY2016 Funding for the Centers for Disease Control and Prevention and the  
National Institutes of Health

### **Submitted By:**

David Kasnic, Executive Director  
Pediatric Congenital Heart Association  
dkasnic@conqueringchd.org

### **INTRODUCTION**

I want to thank Chairman Tom Cole, Ranking Member Rosa Delauro, and members of the committee for the opportunity to provide my testimony on the importance of federal congenital heart disease (CHD) research.

On behalf of the Pediatric Congenital Heart Association (PCHA), I urge Congress to:

- Provide \$10 million in FY2016 to the Center for Disease Control (CDC) and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to support surveillance and public health research that builds upon current activities to better understand the public health impact of CHD across human lifespan, and
- Support the National Institutes of Health's (NIH) life-saving research and efforts to develop innovative and cost-effective treatment options for Americans living with CHD.

### **BACKGROUND ON CONGENITAL HEART DISEASE**

Congenital heart disease (CHD) is a serious public health concern. It is the most common birth defect and leading cause of birth defect-related infant mortality. Nearly 1 in 100 babies are born with CHD, five percent of which will not live to see their first birthday. Even for patients who receive successful medical interventions, there is no cure. Children with CHD require ongoing and costly specialized cardiac care, and face lifelong risks of permanent disability and premature death. As a result, healthcare utilization among the CHD population is significantly higher than the general population. It is estimated that the medical costs for individuals with CHD are 10 to 20 times greater than individuals



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born without birth defects. Hospitalization costs for pediatric CHD patients total more than \$5.6 billion each year, which is 15 percent of all hospitalization costs for patients 20 years of age and younger.

### CONGENITAL HEART FUTURES ACT

Enacted in 2010 as a provision of the Patient Protection and Affordable Care Act, the Congenital Heart Futures Act sought to “enhance and expand public health surveillance of CHDs across the lifespan...facilitate further research into the types of health services patients use, and identify possible areas of educational outreach and prevention.” In 2012 and 2013, approximately \$2 million was appropriated to the CDC for these efforts, with an additional \$1 million provided in fiscal year 2014 and \$4 million appropriated in 2015. These appropriations resulted in innovative CHD public health research initiatives by the CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD). Activities included:

- Facilitating a three-year, multi-site surveillance project on adolescents and adults with CHD;
- Conducting a quality of life and care survey on adult CHD survivors;
- Analyzing existing prevalence data from state and federal sources; and
- Coordinating an expert meeting to identify gaps in knowledge and develop a public health science agenda.

Additionally, the Congenital Heart Futures Act encouraged the NIH to expand, intensify and coordinate research by utilizing resources from the Pediatric Heart Network, a research initiative of the NIH’s National Heart Lung and Blood Institute (NHLBI). The Pediatric Heart Network is a robust multi-centered research network that incites teamwork among CHD researchers, patients and the NIH. The network allows multiple institutions to work together in a “hub and spoke” fashion to bring about collaboration. The Pediatric Heart Network has a proven track record in its ability to ensure researchers work together and share of resources, which has led to medical discoveries in CHD and improved lives.

### PEDIATRIC CONGENITAL HEART ASSOCIATION

The Pediatric Congenital Heart Association’s mission is simple: to “Conquer Congenital Heart Disease.” Working to support the more than 3 million people alive today with heart defects, we work passionately through collaboration in advocacy, education and research to reduce the impact of congenital heart disease while striving to realize a world free from it. Furthermore, I write to you today, not only as a national leader in patient advocacy, but also as the father of an 11-year-old daughter born with a complex CHD and survivor of open-heart surgery.



As the largest source of funding for congenital heart disease research, we urge you, the federal government to help us conquer CHD by continuing to robustly fund CHD research.

## RECOMMENDATIONS

PCHA is concerned about the lack of rigorous epidemiological and longitudinal data on individuals of all ages with CHD. We encourage the Subcommittee to provide additional funding to collect and analyze nationally representative, population-based epidemiological and longitudinal data on infants, children, and adults with CHD. The data is necessary to improve our understanding of the incidence, prevalence and public health impact of CHD.

Additionally, we recommend that the Subcommittee urge the NHLBI to continue to utilize the Pediatric Heart Network's existing infrastructure and assess new opportunities to expand the network. Potential opportunities include growing the number of research centers in the network, increasing collaboration between other federal agencies and incorporating patient community input in the development of the network.

Thank you for the opportunity to provide this written testimony to the Subcommittee. I commend the Subcommittee for its leadership in ensuring federal investments to improve the nation's health outcomes for individuals with CHD do not falter.



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Heart Association

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**House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**Testimony for the Record in Support of Appropriations for the Title V Maternal and Child  
Health Services Block Grant**

**April 29, 2015**

**Submitted by Lori Tremmel Freeman  
Chief Executive Officer of the Association of Maternal & Child Health Programs.**

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Chairman Cole and Distinguished Subcommittee Members:

I am grateful for this opportunity to submit written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women and children that are served by the Title V Maternal and Child Health (MCH) Services Block Grant. I am asking the Subcommittee to support an increase of \$2 million in funding for the Title V MCH Services Block Grant for a total of \$639 million for federal fiscal year 2016.

These funds are needed to extend evidence-based services and strategies that further the program's statutory purpose to improve the health of all mothers and children by 1) ensuring access to quality maternal and child health services, 2) reducing infant mortality and preventable diseases and conditions, and 3) providing and promoting family centered, community-based, coordinated for children with special health care needs and facilitating the development of community-based systems of services for such children and their families.

I know you and your colleagues understand that this level of funding does not allow us to address all the health needs of our nation's women, children, fathers and families. Despite recent progress, close to 24,000 babies tragically die each year. Many others are born too soon and cost our society upwards of \$26 billion per year. Gaps in both private and public insurance create barriers for families needing services. Many pregnant women still smoke. The obesity epidemic continues to plague our country and the list goes on and on. In the face of these challenges, public health programs have already borne more than their fair share of deficit reduction with years of cuts and a budget cap that could cut funding even further. In total, more than 52,000 state and local public health jobs have been lost since 2008 due to the elimination of positions, hiring freezes, layoffs and furloughs. This represents a loss of 17 percent of the state and

territorial public health workforce and a 22 percent loss of the local public health workforce, with serious consequences for our capacity to address leading MCH challenges.

However, we recognize that during these tough budgetary times any substantial increase in funding would come at the detriment of other public health programs. Therefore, we strongly urge you to support a small \$2 million increase in funding for the federal investment in the Title V MCH Services Block. Title V has proven to be a cost effective, accountable, and flexible funding source used to address the most critical, pressing and unique MCH needs of each state. States and jurisdictions use the Title V MCH Block Grant to design and implement a wide range of maternal and child health programs that respond to locally defined needs.

One of the most exciting developments with the Title V MCH Block Grant is a transformation that is happening right now under the leadership of Dr. Michael Lu, associate administrator of the Health Resources and Services Administration Maternal and Child Health Bureau. This transformation is focused on three main goals – to reduce burden, maintain flexibility and improve accountability. At its center is an effort to improve our performance measurement framework with a sharpened focus on national outcome measures, national performance measures and evidence-based strategy measures.

This transformation will ensure that investments made by the programs support evidence-based or informed strategies. Title V focuses on accountability and delivering results, and we are confident this transformation will build and strengthen that important focus so you can be assured that we are getting the best value for the taxpayer dollar while making real and measurable differences in the lives of our mothers and children. For more information on this effort, please contact me and my staff will help arrange further briefing and information on what this means for your state.

A key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of state Title V, Medicaid and the Children's Health Insurance Program (CHIP) by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home child care facilities.

One of the primary focus areas for states Title V programs is supporting systems of services for children and youth with special health care needs (CYSHCN). These systems serve a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. Overall,

CYSHCN are defined as children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. In a recent national survey, children with a chronic condition birth to age 18 represented approximately 15 percent of the entire child population in the United States.

Creating a comprehensive, quality system of care for children and youth with special health care needs (CYSHCN) has been one of the most challenging areas for state health leaders and other stakeholders such as state Title V CYSHCN programs, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, and families. By one critical measure, only 43 percent of all CYSHCN report receiving services via a recommended medical home. Medical homes are considered the gold standard because they promote care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Recently AMCHP – with the generous support of the Lucile Packard Foundation for Children’s Health and a broad group of stakeholders – forged a project that we believe accelerates progress in this challenging area. For more than three decades, numerous national reports, initiatives, and research have described or called for frameworks, standards and various measures to advance a comprehensive system of care for CYSHCN and their families. These and other efforts have helped to establish important work in states, communities, health plans, provider practices, and other areas to build comprehensive systems of care for CYSHCN. However, until recently they have not resulted in an agreed on national set of standards that could be used and applied within health care and public health systems and other child-serving systems to improve health care quality and health outcomes for this population of children. It became clear to AMCHP and others that achieving consensus on the necessary capacity and performance of systems serving CYSHCN is essential to comprehensive, quality systems of care for this population of children.

To pursue this vision, AMCHP recently led a *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* project to develop a core set of structure and process standards for systems of care for CYSHCN, based on the research and national consensus among a diverse group of stakeholders with expertise in their field. The resulting standards – available on our website - are intended for use by a range of national, state and local stakeholder groups including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children’s hospitals, insurers, health services researchers, families/consumers and others. These standards represent a major breakthrough that can help improve our system of care for all children – and this committee can help further accelerate progress by assessing the resources needed to make sure every state has the capacity to fully operationalize and implement them.

In our view, one of the biggest under-celebrated success stories of recent times are the contributions this committee makes in funding programs such as the Title V MCH Services

Block Grant that contribute to substantial progress in reducing infant mortality. In fact, a few months ago President Obama responded to a question about priorities in media coverage by saying in an interview, "There's just not going to be a lot of interest in a headline story that we have cut infant mortality by really significant amounts over the last 20 years..." He noted that plane crashes and terrorism are more likely covered, and that other complex stories are harder for the media to report.

He's right, and yet those who take a closer look will find that in 2013, 23,440 babies in the United States died in their first year of life, which *is* equivalent to about 117 average sized passenger planes crashing every year. That's close to one every three days. The president also is right that we made tremendous progress in reducing that toll in recent decades – as mentioned, perhaps one of the greatest public health success stories rarely covered in the press.

For a long time, infant mortality rates have been one of the sentinel measures to gauge how well any society is doing to ensure the health of women, children and families. **And here is the headline news: since we began collecting statistics in 1915, the overall infant mortality rate declined from nearly 100 of every 1,000 babies born in 1915 to nearly just 6 per 1,000 in 2011. That is a stunning 94 percent improvement and represents millions of lives saved.**

Ensuring that babies are born in optimal health is all the more important considering the recent scientific advances in our understanding about how a baby's early years are critical to building a strong foundation for the rest of their life course. That is the good news – but there also are a few caveats and contradictions. First, there are persistent and unacceptable disparities among racial and ethnic groups that have existed since the data collection began. The black and Native American infant mortality rates are twice the rates of whites, and in some communities it is even three times higher.

The second caveat is that the political will to accelerate progress and eliminate disparities is inconsistent. Perhaps the biggest contradiction is that the United States spends more money on maternity care than any other nation on earth, yet still lags behind 26 other industrialized nations on the key outcome of infant mortality.

Part of the problem is that too often we spend more on high tech treatments – think elective C-sections and neonatal intensive care units – than on basic prevention programs to address risk factors that can lead to poor birth outcomes. For example, we know that breastfeeding, family planning, immunization, smoking cessation and safe sleep are effective in reducing infant mortality. However, funding levels for these key public health programs have never matched actual need, have slowly eroded over time, and are suffering further threats from budget caps and looming sequestration.

Additionally, in June 2012, then Secretary of Health and Human Services Kathleen Sebelius called for the first ever National Strategy to Reduce Infant Mortality. A federally appointed



committee submitted detailed recommendations but, to date, no formal strategy has been adopted.

Congress of course has the power of the purse, but has not consistently delivered on its obligation to annually review programmatic funding levels for public health programs and match resources to national needs. Instead, it has allowed the slow erosion of critical programs like the Title V MCH Block Grant – which has a statutory purpose to reduce infant mortality – by imposing cuts of close to \$100 million over the past decade.

Currently funded at \$637 million, this preventive program represents less than one day's worth of the nation's spending on the Medicaid program, which at \$1.2 billion a day reached a total of \$450 billion in 2013. This demonstrates once again that our health system spends plenty on health *care* but invests precious little in *prevention* and public health efforts. In terms of total potential cost savings to our health system, far too little attention is consistently given to health economics and the measurable financial impact of public health and the prevention of disease, illness and early death.

To move forward, we suggest four things: 1) your committee could ask the current leadership of the U.S. Department of Health and Human Services to take another look at the existing recommendations and deliver on the promise to create a national strategy to reduce infant mortality; 2) your committee could take a close look at that strategy, ask for briefings, assess where improvement is possible, and provide the resources and leadership needed to bring proven efforts to scale; 3) members of this committee and your colleagues can visit and highlight the communities where public health efforts are succeeding to help create the political will to accelerate those successes; and 4) you can support the small \$2 million increase in funding for the federal investment in the cost effective and accountable Title V MCH Block Grant.

Taken together, this should generate some interest in headline stories and more importantly, help ensure that every baby that enters this world is born healthy and loved.

**About AMCHP:** The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. AMCHP's members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community based family health professionals, as well as families themselves. For additional information, please reach me at 202-775-0436 or [lfreeman@amchp.org](mailto:lfreeman@amchp.org).

**Testimony of Thomas A. Teasdale, DrPH, MPH**  
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*Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies –*

*Addressing the Health Resources and Services Administration (HRSA)*

As the Director of a Geriatric Education Center serving Oklahoma, and as a board member of the National Association for Geriatric Education (NAGE), I am pleased to submit this statement for the record recommending at least **\$44.7 million in Fiscal Year 2016 to support geriatrics programs** under the newly named *Geriatrics Workforce Enhancement Program (GWEP)* administered by the Health Resources and Services Administration (HRSA).

The Health Resources and Services Administration (HRSA) recently combined the geriatric education programs in Titles VII and VIII (approx. \$37.7 million for FY15) along with portions of the Alzheimer's Disease Prevention, Education, and Outreach Program (approx. \$4 million for FY15) to establish the Geriatrics Workforce Enhancement Program (GWEP). The GWEP is now the only federal program designed to improve health care quality and safety, plus reduce cost of care through appropriate training of health care professionals, caregivers, and direct service workers who care for older adults. Applications from across the country to receive initial GWEP funding are currently under review. Proven results from activities under the predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of health care providers and family

caregivers better prepared to support older Americans. Therefore, we request a total of at least \$44.7 million for these programs; a minimum of \$39.4 million for the GWEPs programs under Titles VII and VIII (4.5% increase), and \$5.3 million for the Alzheimer's Disease Prevention, Education, and Outreach Program (3.3% increase), both of which are critical to caring for the elderly population.

My colleagues from across the nation recognize that the Subcommittee faces difficult decisions in a constrained budget environment, but we believe that a continued commitment to programs supporting the growing need for geriatric education programs that help the nation's health professions better serve the older and disabled population should remain a top priority. The nation faces a shortage of geriatric health professionals. Every day in America 10,000 more persons reach the age of 65 years. There simply are not enough geriatricians, geriatric nurse practitioners and the many other health professions trained in geriatrics needed to provide interprofessional care to this rapidly increasing older population. I believe that funding for GWEP-based geriatric education supports your important work to establish a sustainable future for the Social Security system by ensuring that (a) health care specialists trained in geriatric care do not become a rare and expensive resource and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

Under the new structure of GWEP, forty newly funded education centers will continue much of the work currently conducted by retired Geriatric Education Centers (GEC), Comprehensive Geriatric Education Programs (CGEP), Geriatric Academic Career Awards

(GACA), and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers (GTPD). A primary purpose of these GWEP centers will be to continue training health care professions faculty, students, and field practitioners in the interprofessional diagnosis, management and prevention of disease, disability, and other chronic health problems of the elderly.

HRSA's FY2015 Justification of Estimates for Appropriations Committees notes that for the 2013 reporting year, these programs accomplished an extraordinary amount of work:

- GEC programs provided over 1,650 different continuing education courses to over 94,000 trainees, exceeding the program's performance goal by 58.5%. Almost half of GEC grantees offered training at primary care settings and/or in medically underserved communities.
- CGEP grantees offered over 150 different CE courses to over 11,600 trainees across the health professions.
- GACA programs supported 62 faculty awardees who delivered over 1,100 different courses, workshops and other types of training activities to over 53,000 trainees across the health professions.
- GTPD programs supported 64 faculty fellowships that helped train and retain physicians, dentists, and behavioral and mental health professionals who plan to teach geriatrics in their selected fields. The majority were trained in Veteran's Affairs hospitals, private hospitals and academic centers with nearly half of the sites located in medically underserved communities. Notably, each participant dedicated at least 25% of their time for teaching

health students about geriatric-related topics via more than 275 courses, workshops and other activities.

New GWEP awardees will be authorized to provide to family caregivers and direct service workers instruction on prominent issues in the care of older adults, such as Alzheimer's disease, dementia, palliative care, self-care, chronic disease self-management, and maintaining independence, among others.

Geriatric education programs in Titles VII and VIII have improved the education, supply, distribution, diversity, and quality of health care professionals who care for our nation's growing older adult population, including the underserved and minorities. We need your continued support for geriatric programs to adequately prepare the next generation of health professionals for the rapidly changing and emerging needs of the growing and aging population.

On behalf of those who have benefitted in Oklahoma and my colleagues around the country, thank you for this opportunity to share our request for support for these important programs. We ask that you thoughtfully consider our request for funding in FY 2016.

NAGE is a non-profit membership organization representing Geriatric Education Centers (GECs) and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology.

**Monika Johnson Hostler  
Board President  
National Alliance to End Sexual Violence**

**Testimony Presented For the Record**

**United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**

**April 29, 2015**

On behalf of the National Alliance to End Sexual Violence (NAESV) representing 56 state and territorial sexual assault coalitions and more than 1300 local rape crisis centers, I am respectfully requesting FY 2016 federal funding to support comprehensive rape prevention and education and direct services for victims of sexual violence. Specifically, NAESV is urging Congress to provide \$44.4 million for the program and \$5.6 million for evaluation for the Rape Prevention & Education Program (RPE) in the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control budget. In addition, NAESV is requesting level funding of \$160 million for the Preventive Health and Health Services Block Grant, which includes a \$7 million set-aside for rape prevention services, in CDC's State, Tribal, Local and Territorial Support program budget. Together, we must make our communities safer.

One in five women has been the victim of rape or attempted rape. Nearly one in two women has experienced some form of sexual violence and one in five men has experienced a form of sexual violence other than rape in their lifetime. The CDC National Intimate Partner and Sexual Violence Survey study confirmed that the impacts of sexual violence on society are enormous. Over 80% of women who were victimized experienced significant short and long-term impacts

related to the violence such as Post-Traumatic Stress Disorder (PTSD), injury (42%) and missed time at work or school (28%). The CDC report also shows that most rape and partner violence is experienced before the age of 24, highlighting the importance of preventing this violence before it occurs.

The 2014 Rape Crisis Center Survey, distributed by NAESV, demonstrated that over ¼ of rape crisis centers had to decrease the number of prevention education services due to insufficient funding while almost 20% of these programs could not provide services within one month of a request; 1/3 of the rape crisis centers had a waiting list for services and more than 40% lost staff. High profile cases of sexual assault on campuses, our military bases, military academies, and by celebrities and professional athletes have resulted in unprecedented media attention. This has also resulted in a tremendous increase in sexual assault survivors seeking assistance from local rape crisis centers, as well as educators and community organizations requesting prevention and training services. The media attention certainly points to the need for comprehensive community responses to sexual violence like those funded through the Rape Prevention and Education program and the Preventive Health and Health Services Block Grant. As you begin the FY 2016 appropriations process, please fund these programs so critically important to the prevention and response to sexual assault.

**Rape Prevention and Education (RPE)** – The National Alliance to End Sexual Violence urges Congress to provide \$44.4 million for the program and an additional \$5.6 million for RPE program evaluation, with the goal of creating a more extensive evidence base for sexual violence prevention. Funding for RPE through CDC's Injury Center provides formula funding to every

state and territory to raise awareness of the problem of sexual assault, support efforts to prevent first-time perpetration and victimization, and brings together diverse partners to develop, implement and evaluate statewide sexual assault prevention plans. The RPE program engages boys and men as partners, supports interdisciplinary research collaborations, fosters cross-cultural approaches to prevention, promotes healthy relationships, and funds the critically important National Sexual Violence Resource Center. High profile cases have increased the demand for prevention and education beyond the current capacity of state sexual assault coalitions and local rape crisis centers. The expansive media attention also points to the need for comprehensive community responses to sexual violence like those funded by RPE. Utilizing FY 2013 funding, the state sexual assault coalitions and local rape crisis centers educated more than 1.8 million students, answered 340,000 hotline calls, and conducted over 105,000 trainings nationwide.

Formula Shortfall - Beginning in FY 2014, a new RPE funding formula was implemented based on VAWA 2013. While the formula provides a base funding of \$150,000 for all 50 states, Washington, DC and Puerto Rico, and \$50,000 for territories, it reduces the funding provided to large states. In addition, CDC is altering the fiscal year of the program which resulted in reduced funding stretched over a span of 15 months, further penalizing state coalitions and local rape crisis centers at the same time demand for rape prevention and education is increasing due to high profile cases causing alarm in local communities. Increased funding is required to avoid critical shortfalls at a time of increased awareness and demand for prevention and education.



Program Evaluation - There is a need to increase the evidence base for sexual violence prevention. However, those efforts should be funded by additional funding – not from program funds to states and local rape crisis centers. Most recently, CDC decided to make “state level evaluation” mandatory despite many states starting local, regional or targeted evaluation efforts. It is the CDC’s stated perspective that this would be “less labor intensive.” However, this strategy forces everyone down one path, without a recognition of the work and progress that is currently underway in many states, nor of each state’s individual goals, projects or bandwidth to accomplish the work. To date, CDC has not demonstrated that they have developed any significant sexual violence specific research and evaluation over the years. Rather, all indicators suggest that they are relying on proxy measures that have been developed for other issues such as alcohol use, which are not suited to measure sexual violence. We support the CDC’s proposed budget request for evaluation funds, but not at the expense of program funding. We do not want program funds diverted from the communities at a time when demand for prevention and education, as well as services, is increasing at such a rapid rate.

Preventive Health & Health Services Block Grant (PHHSBG) – We are very grateful for the FY 2015 funding of \$160 million enacted by Congress and disappointed with the Administration’s efforts to eliminate the program which provides much needed resources to communities. The Public Health Service Act of 2010 authorizes the block grant and CDC recently moved its administration from Chronic Disease to State, Tribal, Local and Territorial Support. Congress provided a rape set-aside provision which guarantees at least \$7 million for rape services and prevention. Please retain the block grant funding that supports local rape crisis centers providing services, statewide training and technical assistance to increase capacity to

assist rape victims and prevent future victimization. Maximum funding is requested.

We must have the resources to meet the education and prevention needs in the community. Victims deserve support, our young people deserve to grow up safely, and research tells us that appropriate and early intervention and prevention can mitigate the costs and consequences of sexual violence and prevent that violence from occurring in the first place. The best way to prevent victimization is to prevent first time perpetration. The best way to convict a rapist is to support and advocate for the victim, obtain evidence and provide assistance and training to law enforcement. At this time of increased media attention and increased demand for services, now is the best time for the implementation of prevention strategies.

Thank you for the opportunity for the National Alliance to End Sexual Violence to present testimony for the record as the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies begins the process to prepare the FY 2016 Appropriations Bill. If you need further information, I can be reached at 919-871-1015, [monika@necasa.org](mailto:monika@necasa.org) and [www.endsexualviolence.org](http://www.endsexualviolence.org).



## NATIONAL CONGRESS OF AMERICAN INDIANS

### Testimony to the House Appropriations Committee, Subcommittee on Labor, Health and Human Services, Education and Related Agencies

April 29, 2015

The National Congress of American Indians (NCAI) is the intergovernmental body for American Indian and Alaska Native tribal governments. For over sixty years tribal governments have come together as a representative congress through NCAI to consider issues of critical importance to tribal governments and endorse consensus policy positions. NCAI appreciates the opportunity to offer the following testimony on tribal programs in the Departments of Labor, Education, and Health and Human Services.

Numerous treaties, statutes, and court decisions have created a fundamental contract between tribal nations and the United States: tribes ceded millions of acres of land that made the United States what it is today, and in return tribes have the right of continued self-government and the right to exist as distinct peoples on their own lands. And for its part, the United States has assumed a trust responsibility to protect these rights and to fulfill its solemn commitments to Indian tribes and their members. Part of this trust responsibility includes basic governmental services in Indian Country, funding for which is appropriated in the discretionary portion of the federal budget.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

In addition to requests below, NCAI supports the testimony of the National Indian Child Welfare Association in their testimony for programs funded in the Department of Health and Human Services.

Head Start: NCAI requests \$9.6 billion in total funding for Head Start, which includes Indian Head Start. Head Start has been and continues to play an instrumental role in Native education.

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Head Start funds provide early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate.

Administration for Native Americans, Native Languages Preservation: Native language grant programs are essential to revitalizing Native languages and cultures, many of which are at risk of disappearing in the next decade. NCAI requests \$12 million as part of the appropriation to the Administration for Native Americans for Native language preservation activities.

Low-Income Home Energy Assistance Program (LIHEAP): Provide \$4.7 billion for LIHEAP, with \$51 million allocated to tribes and tribal organizations. The LIHEAP is intended to assure that low-income families will not be forced to choose between food and heat. With high unemployment and long-standing barriers to economic development, much of Indian Country cannot afford the rising costs of heat and power. Alaska Native villages are experiencing some of the highest costs for energy with fuel prices recently reaching \$7 per gallon. Full funding is crucial to address the extreme need for heating assistance in Indian Country. Accordingly, funding for FY 2016 should be \$51 million for tribes.

### **Substance Abuse Mental Health Services Administration**

Programs of Regional and National Significance: Tribal Behavioral Health Program: NCAI requests \$50 million for this initiative. The Consolidated Appropriations Act of 2014, Pub. L. No. 113-76 (2014) recommended that \$5 million be allocated to Tribal Behavioral Health Grants (Native Connections Grants). These are competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. Unlike other groups where the suicide rate increases with age, American Indian/Alaska Native (AI/AN) rates are highest among the youth and decrease with age. AI/AN young people are more likely than other youth to have an alcohol use disorder.<sup>i</sup> Although these statistics are troubling, with adequate resources tribes are best able to

serve these young people and help them heal before they reach adulthood. Current Native Connections grants focus more specifically on youth and, due to the level of funding, is a competitive program available to approximately 20 tribes based on the per capita suicide rate and application. Increased funding would allow more tribes to have access to this vital funding.

#### **Administration for Community Living (ACL)**

Native American Nutrition and Supportive Services: NCAI recommends \$30 million for this program in FY 2016. This program is the primary vehicle for providing nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. These grants support a broad range of services to older Native Americans, including adult day care; transportation; congregate and home-delivered meals; information and referral; and personal care, chore, and other supportive services. ACL's meal program reaches just 24 percent of eligible American Indians, home-delivered meals reach 12 percent of such persons, and supportive services reach 41 percent. These programs help to reduce the need for costly nursing home care and medical interventions. This program should be funded so that Native elders receive the care that they deserve.

#### **CENTERS FOR MEDICARE & MEDICAID SERVICES**

NCAI supports the testimony of the National Indian Health Board and W. Ron Allen, Tribal Chairman/CEO, James S'Klallam Tribe, Vice-Chairman for the Indian Health Service Tribal Self-Governance Advisory Committee (TSGAC), member of Secretary Burwell's Tribal Advisory Committee (STAC), and Chair of the Tribal Technical Advisory Committee as to their testimony before this Committee, dated April 23, 2015, and the recommendations made specific to the Centers for Medicare & Medicaid Services and implementation of the Affordable Care Act.

**DEPARTMENT OF EDUCATION**

In addition to requests below, NCAI supports the testimony of the American Indian Higher Education Association and National Indian Education Association.

State-Tribal Education Partnership (STEP) Program: NCAI requests \$5.6 million for the State-Tribal Education Partnership Program. Congress appropriated roughly \$2 million dollars for the STEP program to five participating tribes under the Tribal Education Department appropriations. For this program's continued success, it must receive its own line and appropriation in FY 2016. Collaboration between tribal education agencies and local and state educational agencies is crucial to develop the tribal capacity to assume the roles, responsibilities, and accountability of Native education departments and to increase tribal self-governance over Native education.

Title VII (Indian Education Formula Grants): NCAI requests \$198 million for Title VII funding under the No Child Left Behind Act. Current funding for Title VII, Part A decreased by \$6 million to \$124 million under sequestration and has been maintained at that level in Fiscal Years 2014 and 2015. Increases are needed as this critical grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain parity with their non-Native peers.

Indian Education Language Immersion Grants: NCAI requests \$5 million under the creation of Title VII, Part D of the No Child Left Behind Act. According to the United Nations Educational, Scientific and Cultural Organization (UNESCO), 74 Native languages stand to disappear in the next decade, with only 20 Native languages being spoken by 2050. Funding would strengthen tribal sovereignty by amending ESEA Title VII to create a grant program that increases tribal capacity to support Native language immersion schools and provide Native students equal access to learning their cultures and languages. Creating Part D would modernize ESEA Title VII to protect the

cultural and linguistic heritage of Native students in education systems by providing Native students full-day immersion learning in order to strengthen their language, improve academic outcomes, and become future leaders of their tribes.

## **DEPARTMENT OF LABOR**

Employment and Training Administration, Indian and Native American Program: NCAI recommends the Department of Labor's Indian and Native American Program (INAP) at a minimum of \$60.5 million. The Workforce Improvement Act (WIA) Section 166 program serves the training and employment needs of over 30,000 American Indians and Alaska Natives through a network of 175 grantees funded under the Comprehensive Service Program (Adult), the Supplemental Youth Service Program (Youth), and the Indian Employment and Training and Related Services Demonstration Act of 1992, Public Law 102-477. Funding reserved for INAP grantees is distributed directly to tribes from the Department of Labor, and not first dispersed to the states for later tribal distribution in keeping with the sovereign status of tribal nations. Funding of this program has not been adjusted to account for the drastic changes in the economic environment and growth in population since the 2000 Census and, in FY 2015, was below the statutory required minimum.

## **CONCLUSION**

Thank you for the opportunity to share these views with the Subcommittee. The needs in Indian Country are great and we thank this Subcommittee for working to honor the treaties and agreements made between our ancestors.

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<sup>i</sup> Office of Applied Studies, Substance Abuse and Mental Health Services Administration. (2007). Substance use and substance use disorders among American Indians and Alaska Natives. The National Survey on Drug Use and Health Report. Retrieved from <http://oas.samhsa.gov/2k7/AmIndians/AmIndians.htm>



Protection & Advocacy for  
Persons with Developmental  
Disabilities

Protection & Advocacy for  
Individuals with Mental  
Illness

Protection & Advocacy of  
Individual Rights

Protection & Advocacy for  
Assistive Technology

Protection & Advocacy for  
Individuals with  
Traumatic Brain Injury

Protection & Advocacy for  
Beneficiaries of Social Security

Protection & Advocacy for  
Voting Accessibility

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**Person Submitting Testimony:** James Tucker, J.D., Executive Director,

Alabama Disabilities Advocacy Program

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor,  
Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS)  
Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) and by facsimile

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I am James Tucker, Executive Director of the Alabama Disabilities  
Advocacy Program (ADAP), the Protection and Advocacy (P&A) agency for  
Alabama. I write to submit testimony for the record demonstrating how  
ADAP protects persons with intellectual and developmental disabilities  
(I/DD) from abuse and neglect, promotes their community integration,  
and ensures their access to services.

Since its enactment in 1975, P&A agencies through the Protection  
and Advocacy for Individuals with Developmental Disabilities (PADD)  
program have been working to ensure that individuals with I/DD are free  
from abuse and neglect (both in institutional settings and the community)  
and that their rights and desires are respected and considered as  
decisions are made concerning education, employment, housing, and  
health care.



In FY14, ADAP served 300 individual clients with I/DD. We conducted 49 trainings attended by 1,800 consumers, families and/or community providers. We provided informational and referral services to 701 people with I/DD and/or their family members. In addition to these activities, 241,263 people with I/DD were impacted by the activities undertaken by ADAP on behalf of groups of clients.

Before describing examples of recent work ADAP has undertaken related to community integration and services for persons with I/DD, I want to provide some context that explains the focus of our recent work: Alabama was the first southern state to close all its public institutions for person with intellectual disabilities (ID) and transition to a community-based system. The state's last state-run institution for persons with ID—the Partlow Developmental Center—closed in December 2011. During the last year of Partlow's existence, ADAP participated in transition planning to ensure that proper community services, supports, and placements of the consumer's choice were identified for each of the facility's remaining 151 residents. Early on in the transition process, ADAP focused especially on those persons with ID who had significant health care needs and/or were elderly, advocating with the state for enhanced planning services for those individuals. After placement, ADAP followed up with each of the 151 individuals in their community settings to ensure their transitions went well and the individuals were being properly supported in their new homes. One such individual was "Ken." Ken entered Partlow at the age of 5. After living in the facility for 41 years, Ken moved to a three bedroom group home where he was living with two other gentlemen and a care staff member. At the time of ADAP's visit to Ken's new home, he was excited about getting ready to attend the Christmas Formal hosted by the local Arc provider at the nearby Sheraton Hotel. Ken and

his housemates were going on weekly outings, including to restaurants, attending church, picnics, and shopping. The staff at the group home recently had a dinner party at the home for Ken and his housemates and invited others over. ADAP witnessed experiences like Ken's over and over again during our monitoring, as Partlow residents settled into their new homes for life outside the facility's gates.

Since the state's transition to a totally community-based I/DD service delivery system, ADAP's work has focused on ensuring the safety and well-being of persons with I/DD in the community and enhancing their opportunities for successful community integration. To achieve these outcomes for our clients, ADAP conducts community-based monitoring, as allowed under our federal enabling statutes, including PADD. During FY14, ADAP monitored in 24 group homes and in ten sheltered workshops/day habilitation programs for persons with I/DD. We also did individual casework to protect and promote the safety and rights of persons with I/DD, including examples like the following:

"Ernest" is 50 years old and has an intellectual disability (ID). ADAP received an anonymous letter alleging that medication, food and toiletry supplies for Ernest and his housemates were being stolen and misused by staff working in the group home. The anonymous letter stated Ernest was always out of diapers and wipes. The letter also reported staff sleep on night shift and eat the clients' food. ADAP conducted an investigation of the reported allegations. It consulted with the provider agency which runs the group home and reviewed the agency's own investigation into the allegations. ADAP determined that food and toiletries were not being stolen but, rather, the Qualified Developmental Disabilities Professional (QDDP)—the provider staff responsible for Ernest's supports and services—was locking up food

and supplies and not providing staff access to it. As a result of the QDDP's practice of rationing out the food and supplies and locking the rest in an inaccessible closet, there was a general shortage of food and hygiene supplies. ADAP substantiated the allegation of neglect and mistreatment. The QDDP was terminated.

"Mary" has cerebral palsy and was having difficulties living safely in the community. As a result, the state's Adult Protective Services (APS) program become involved with Mary and sought an adult protective services order and guardianship for her. Mary's mother contacted ADAP asking us to help. With guidance from ADAP, Mary was able to obtain Medicaid-funded services that alleviated APS' concerns. The guardianship and continuing protective services were unnecessary and the court case brought by APS was dismissed. As a result of ADAP's efforts, Mary is being appropriately served in the community, retaining her independence and right to self-determination.

"Charlotte" is 26 years old and has an ID. Her mother contacted ADAP after Charlotte had been hospitalized for self-injurious behavior including head-banging and attempting to stab herself with a pen. Charlotte was living in the community with few support services. ADAP discussed with Charlotte and her mother about whether Charlotte would benefit from home and community-based Medicaid waiver services. As a result of ADAP's intervention, Charlotte was approved for waiver services and, upon her release from the hospital, Charlotte began receiving residential and day program services, allowing her to live safely and meaningfully in the community.

"Brittany" is 23 years old and has an ID and cerebral palsy. Brittany requires 24 hour care and supervision. Brittany's father had already quit his job to stay at home and care for his

daughter and Brittany's mother was in jeopardy of losing her job given the time she had to take off to assist her husband. The family was at risk of losing its home when Brittany's mother and father contacted ADAP for help. As a result of ADAP's intervention, Brittany was approved for home and community-based Medicaid waiver services, providing her day habilitation services and 40 hours/week of personal care services. These services are allowing Brittany to live successfully in the family home and are allowing her mother and father to regain financial and personal stability in their lives while they care for their daughter.

I appreciate the opportunity to share with you this snapshot of ADAP's work on behalf of persons with I/DD and welcome any questions or comments.

Testimony Submitted by the American Congress of Obstetricians and Gynecologists (ACOG)  
Contact Person: Mary Schilling, Federal Affairs Manager, mschilling@acog.org, 202-863-2512  
To the US House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services and Education, and Related Agencies  
Department of Health and Human Services (HHS)

The American Congress of Obstetricians and Gynecologists (ACOG), representing 58,000 physicians and partners in women's health care, is pleased to offer this statement to your subcommittee, and we thank Chairman Cole and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to women's health. Today, the US lags behind many other nations in healthy births. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative would help improve maternal and infant health through federal research investments, including comprehensive data collection and surveillance, biomedical research, and translating research into evidence-based care for women and babies. **We urge you to support the following funding levels, at a minimum, for these programs and initiatives within CDC, NIH, HRSA, and AHRQ in FY16:** \$172 million for the National Center for Health Statistics within CDC, including \$5 million dedicated to modernizing the National Vitals Statistics System; adequate funding to expand Pregnancy Risk Assessment Monitoring System to all US states and territories; \$32 billion for NIH including \$1.37 billion for the National Institute on Child Health and Human Development; \$639 million for the Maternal Child Health Block Grant at HRSA; \$327 million for Title X at HRSA; \$0.5 million for Fetal Infant Mortality Review programs within Healthy Start at HRSA; \$2 million for a pre-term birth sub-line as authorized by PREEMIE, at CDC, as well as \$46 million to implement PREEMIE and help states expand or establish Maternity and Perinatal Quality Collaboratives. ACOG also supports the use of existing funds towards establishing a federal work group to improve coordination and provide guidance on how clinical research might be appropriately done regarding pregnant and breastfeeding women and encouraging the Consumer Assessment of Healthcare Providers and Systems program at AHRQ to develop a maternity care-oriented assessment.

**National Center for Health Statistics (CDC): \$172 million requested, \$5 million of which we urge you to designate to modernize the National Vitals Statistics System.** In order to conduct robust research, uniform, accurate and comprehensive data collection is critical. The National Center for Health Statistics is the nation's principal health statistics agency and collects raw vital statistics from state records like birth and death certificates. This information provides key data about both mother and baby during pregnancy, labor, and delivery. Effective data collection depends on all states and territories using electronic birth and death records based on the same 2003 US-standard certificates. Although all 50 states are expected to have the electronic birth record systems available by the end of 2015, there are 5 states still in the early stages of planning and implementing the electronic death registry system. Even in states where the overall systems have been implemented, there remains a need for expanded access and increased training in order to utilize these systems effectively. In most states, there remains at least some reliance on paper record-keeping, creating an inefficient hybrid system that compromises the efficiency and accuracy of electronic record-keeping. NCHS needs increased resources to help enroll the remaining states, and to complete the installation and training processes in all states, in order to truly standardize and improve the accuracy of birth and death data collection nationwide.

**Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC: funding requested at an adequate level to expand PRAMS to all US states and territories.** PRAMS surveys new mothers on their experiences and attitudes during pregnancy through questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, CDC researchers and state health departments are better able to identify behaviors and environmental and health

conditions that may lead to preterm births. Only 40 states use the PRAMS surveillance system today, and increased resources are needed to expand this vital program.

**NIH: \$32 billion requested, including \$1.37 billion for the National Institute on Child Health and Human Development (NICHD).** Biomedical research is critical to understanding and reducing the incidence of maternal and infant mortality and morbidity. NICHD's 2012 Scientific Vision identified the most promising research opportunities for the next decade. Goals include determining the causes of prematurity and developing evidence-based measures to prevent it within the next decade, understanding the long-term health implications of assisted reproductive technology, and understanding the role of the placenta in fetal health outcomes.

**Maternal Child Health Block Grant (HRSA): \$639 million requested.** The Maternal Child Health Block Grant at HRSA is the only federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postpartum care, screen newborns for genetic health conditions, deliver immunizations, and prevent childhood injuries. These early health care services often eliminate the need for later costly care. Every \$1 spent on preconception care for a woman with diabetes can save up to \$5.19 by preventing costly complications.

**Title X Family Planning Program (HRSA): \$327 million requested.** Family planning and interconception care are essential to helping ensure healthy women and healthy pregnancies. The Title X Family Planning Program provides services to more than 4.5 million low income men and

women who may not otherwise have access to these services. Title X clinics accounted for \$5.3 billion in health care savings in 2010 alone.

**Fetal Infant Mortality Review (FIMR) at HRSA: \$0.5 million requested, to increase the number of Healthy Start programs that use FIMR.** HRSA's Healthy Start Program promotes community-based programs to reduce infant mortality and racial disparities. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR), which brings together ob-gyn experts and local health departments to address local issues contributing to infant mortality. Today, more than 172 local programs in 32 states find FIMR a powerful tool to help reduce infant mortality and address issues related to preterm delivery. ACOG has partnered with the Maternal and Child Health Bureau to sponsor the National FIMR Program for 25 years.

**Maternal Health Initiative (HRSA): level funding requested.** The Maternal Child Health Bureau launched the Maternal Health Initiative to promote the concept that "healthy moms make healthy babies." As part of this effort, ACOG has convened the National Partnership on Maternal Safety to identify key factors to reduce maternal morbidity and mortality.

**Safe Motherhood, Maternity and Perinatal Quality Collaboratives (CDC): funding level of \$2 million to re-instate the pre-term birth sub-line, as authorized by PREEMIE, and funding level of \$46 million to implement PREEMIE and help states expand or establish Maternity and Perinatal Quality Collaboratives, requested.** The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. Through Safe Motherhood, CDC funds state-based Maternity and Perinatal Quality Collaboratives that improve birth outcomes by encouraging use

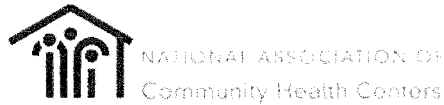


of evidence-based care, including reducing early elective deliveries. The PREEMIE Reauthorization Act, enacted in 2013, authorizes funding to increase the number of states receiving assistance for Perinatal Quality Collaboratives.

**ACOG supports the establishment of a federal work group to improve coordination and provide guidance on how clinical research might be done regarding pregnant and breastfeeding women.** Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed their infants. However, little is known about the effects of most drugs on the woman and her child. Although there have been substantial encouraging developments in this arena, significant gaps remain. In order to achieve meaningful progress, HHS must ensure the coordination of all efforts being made at the agency level.

**Consumer Assessment of Healthcare Providers and Systems (CAHPS) at AHRQ: encourage the CAHPS program to direct funds towards the development of a maternity care-oriented assessment.** The CAHPS program was established within the Agency for Healthcare Research and Quality (AHRQ) to address concerns regarding the lack of available consumer health plan reviews. The information collected through this program can be a critical element of patient decision-making, while also informing providers and insurers about the impact and reception of their initiatives and services. Unfortunately, the CAHPS program has not yet established a survey to collect data about maternity care. Given the frequency and complex nature of interactions that an expectant mother will have with a healthcare system, we support the creation of a CAHPS survey focused on maternity care.

Again, we would like to thank the Committee for its commitment to improving women's health, and we urge you to fund the programs we have identified in our MOMS Initiative in FY16.



**Daniel R. Hawkins, Jr.**  
**Senior Vice President, Public Policy and Research**  
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Testimony to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies

### **Introduction**

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee: on behalf of our nation's health centers, we wish to thank you for the opportunity to submit testimony for the record as the subcommittee begins its work on the Fiscal Year (FY) 2016 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

### **Health Centers- General Background**

Health centers are community-owned and operated non-profit entities providing primary medical, dental, and behavioral health care as well as pharmacy and a variety of enabling and support services. This year marks a momentous occasion in health center history as we celebrate fifty years since the first health centers opened their doors in Boston and the Mississippi Delta. Today, what began as a small demonstration project has evolved into the largest and most successful primary health care system in the United States. In 2013, there were nearly 1,300 health centers operating in more than 9,000 urban and rural communities nationwide, serving as the "health care home" for more than 22 million patients, including nearly 7 million children and more than 268,000 veterans. Health centers operate in all 50 states and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas (or serve medically underserved populations) and are governed by patient-majority boards to ensure

they are responsive to the needs of each individual community they serve. Health centers offer comprehensive care to all residents of the community, regardless of ability to pay or insurance status and offer services on a sliding fee scale. Health centers' unique model of care has resulted in savings to the entire health system of approximately \$24 billion annually. Health center care reduces preventable hospitalizations and emergency department (ED) use, as well as the need for more expensive specialty care. The services provided at health centers save \$1,263 per patient per year when compared to expenditures for non-health center users.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. Health centers employ 156,000 individuals and generate an estimated \$26.5 billion in needed economic activity for communities that need it the most.

#### **FY 2015 Funding Background**

In FY 2015, The Health Centers program received a total of \$5.1 billion in total federal funding. This includes \$1.49 billion in discretionary funding provided by the Health Resources and Services Administration (HRSA) and \$3.6 billion in mandatory funding for health centers through the final year of the Community Health Center Fund. We want to thank the members of this Subcommittee for their strong support of health centers within the Consolidated and Further Continuing Appropriations Act of 2015 to ensure health center funding reaches communities in need.

#### **FY 2016 Funding Request and the Health Center Funding Cliff**

Knowing the demand for comprehensive primary care services persists in many underserved communities, health centers are respectfully requesting Congress and this Subcommittee work to ensure that funding for the Health Centers Program remains whole and does not suffer any funding reductions in FY2016, within either the discretionary or mandatory

funding streams. Continued funding for the Health Centers Program at the FY2015 program level of \$5.1 billion will preserve and continue the high quality cost-effective primary care offered today at health centers across the country and, according to HRSA, reach 28 million patients by next year.

There have been clear signs in recent months Congress also supports maintaining current funding levels for health centers. In March, 271 House members signed a letter led by Reps. Gene Green (D-TX) and Gus Bilirakis (R-FL) and 60 Senators signed a letter led by Sens. Roger Wicker (R-MS) and Debbie Stabenow (D-MI) to their respective LHHS Subcommittees as part of the annual appropriations process. These letters highlighted the important role of health centers and requested the Subcommittees work to ensure the sustainability and viability of the program. Additionally, numerous members on both sides of the aisle and the Capitol have submitted program requests calling for funding at the \$5.1 billion level. This funding level will allow health centers to continue their work in your communities and expand access to primary care.

With regard to the mandatory funding, until the passage of H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015, the Health Center Fund was set to expire on September 30<sup>th</sup>, 2015. We referred to this as the “health center funding cliff.” The Health Center Fund is one portion of the two federal funding streams available to health centers, and in FY15 the Fund represents approximately 70 percent (or \$3.6 billion) of the total funding made available to the Health Centers program by Congress. A recent report issued by NACHC, entitled *Community Health Centers: Past, Present and Future: Building on 50 Years of Success*, revealed the funding cliff would have caused 7.4 million patients to lose access to care at their local health center and nearly 57,000 clinicians as well as other staff would have lost their jobs.

Fortunately, this potentially devastating funding cut was averted and Congress has acted to address the health center funding cliff by extending the Community Health Center Fund for an additional two years as part of H.R. 2. I want to take a moment to thank the members of this Subcommittee for their support and we especially want to thank you for your leadership on addressing the funding cliff. We will certainly look to you to assist in protecting the Health Center Fund to ensure it is utilized for the Health Centers program as intended by Congress. Unfortunately, this fund has already been tapped by the Senate in their recently passed piece of legislation, S. 178, the Justice for Victims of Trafficking Act of 2015. This legislation allows for the annual transfer of between \$5 million to \$30 million of funds allocated for health centers each year to pay for the health services provided to victims of trafficking. While we strongly agree that trafficking victims need access to these important health services, but we do not believe Congress needs to pay for these services by reducing funding allocated for the health care for the low-income and medically underserved. It's a bit like robbing Peter to pay Paul. We hope Congress will reconsider this decision and find a way to fund both of these important programs.

### **Conclusion**

We understand this Subcommittee must make difficult budgetary decisions as you work within the funding limits set for the subcommittee's bill. As the FY2016 appropriations process moves forward, we urge you to maintain current funding levels for our nation's health centers. Despite the progress we have made in expanding the program in recent years, 62 million Americans still lack regular access to primary care and may be seeking care at health centers. Without access to a local health center, many individuals located in medically underserved communities will seek care in emergency departments and hospitals, often waiting until they are

sicker get treatment. This will mean poorer health for these patients and much higher costs to the health care system and to taxpayers.

With our unique model of care, Health Centers can help address these primary care demands in a cost effective manner. However, Health Centers cannot continue to deliver results without a sound financial base and continued future certainty. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Center program. We look forward to working with you and thank you for your consideration.

Name: Paul Kowalski  
Title: Acting Director of Health  
Affiliation: City of New Haven, CT  
Department of Health  
54 Meadow Street, 9<sup>th</sup> Floor  
New Haven, CT 06519

I am writing to you today to express my wholehearted support for continued federal funding for the U.S. Department of Housing and Urban Development's Office of Lead Hazard Control and Healthy Homes in addition to fully restored federal funding for the Centers for Disease Control's Healthy Homes and Lead Poisoning Prevention Program. I, respectfully and humbly, urge you to provide a minimum of \$195 million for HUD's Office of Lead Hazard Control and Healthy Homes, including \$45 million for the Healthy Homes Program and \$29 million for CDC's Healthy Homes and Lead Poisoning Prevention Program in the Fiscal Year 2016 Appropriations Bill. Funding for these programs is essential for supporting communities seeking to protect children from lead poisoning hazards in the home while ensuring children who are at risk of becoming lead poisoned will have access to critical services that can prevent the future onset of disability.

Lead poisoning, which is 100% preventable, remains a significant environmental public health threat. CDC estimates that 535,000 children in the U.S. from one to five years old have blood lead levels above 5 micrograms per deciliter ( $\mu\text{g}/\text{dL}$ ). Childhood lead exposure at these levels can lead to lifelong consequences, including decreased cognitive function, developmental delays, and behavioral problems; very high blood-lead levels can cause seizures, coma, and

even death. Children exposed to lead can lose I.Q. points and are six times more likely to drop out of school than children without harmful lead levels. The annual economic costs to society of lead poisoning alone are over \$50 billion. There is no “safe” level of lead for a child.

There are 24 million homes in the U.S., with lead-based paint hazards jeopardizing the health and development of millions of children. Since its inception in 1993, HUD’s Office of Lead Hazard Control and Healthy Homes has successfully developed programs that have created nationwide over 208,000 lead-safe units, while thousands more have been created tangentially.

Since 1994, the City of New Haven, an old and battered yet proud and vital city of 129,946 (with 10,431 children six (6) years of age and younger), has been fortunate to receive five awards of HUD Lead Hazard Control funding, totaling \$14,230,000, which has created over 1,251 lead-safe housing units. This funding prompted a collaboration of homeowners, parents, faith-based and non-profit housing developers, bankers, health providers and state and city agencies. Through combined efforts there has been a dramatic reduction of the number of reported cases, in New Haven, of childhood lead poisoning; from 420 children at or above 20 µg/dL reported in 1995, the year New Haven received it’s first HUD Lead Hazard Control grant, to 424 children reported at or above 5 µg/dL in 2014. The level of concern for lead poisoning has dropped over the years, from at or above 20 µg/dL to at or above 5 µg/dL, and if we were to report upon the number of children within 1995 who were at or above 5 µg/dL that value would be at least 1,680. New Haven, however, continues to have the most reported cases of childhood lead poisoning of any city within the state and therefore lead remains a serious hazard to children in New Haven.



HUD's Office of Lead Hazard Control and Healthy Homes activities to reduce health and safety hazards in housing units save billions of dollars by improving housing stock and neighborhoods while decreasing medical and special education costs. Educational system costs alone are estimated at \$38,000 over three years per child with lead poisoning. Studies show a return of \$17-\$221 per dollar invested in lead hazard control and a net savings of \$181-269 billion. Funding for HUD's Office of Lead Hazard Control and Healthy Homes at a minimum of \$195 million in FY 2016 is crucial to its continued success and will reduce preventable medical and education costs, strengthen the economy, and keep children healthy. In previous funding cycles, HUD has been funded at \$120 million, although previously \$140 million was allocated towards these programs. An award amount of \$120 million prevented half of the qualified applicants, which sought this funding, to receive a grant award.

During the last two decades, CDC has delivered a cost-effective program to prevent lead poisoning and help children who have already been exposed to lead. By maintaining a national surveillance system that monitors blood test results for four million children each year, CDC assists state health and housing agencies to best target funds and enforcement to the highest risk areas.

A FY 2016 funding level of \$29 million for CDC's Healthy Homes and Lead Poisoning Prevention Program would allow 36 sites to go beyond surveillance activities to implement much needed prevention strategies to control or eliminate sources of lead in environments of at-risk children. This level of funding is crucial to allowing the CDC to fund state and local health departments who screen children and/or ensure lead-poisoned children receive medical and environmental follow-up, and prevent childhood lead poisoning through neighborhood-based approaches.

I strongly urge funding for these programs at the levels discussed above. In my thirty-five (35) years of public health never before have I imagined the prospect of finally envisioning the end of childhood lead poisoning. Please assist the U.S. Department of Housing and Urban Development's Office of Lead Hazard Control and Healthy Homes and the Centers for Disease Control's Healthy Homes and Lead Poisoning Prevention Program make this a reality.

Thank you.



April 28, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the American Counseling Association (ACA), the country's largest and oldest counseling association; representing over 55,000 professional counselors, I am writing to you today to request that you provide \$50 million in funding in the Fiscal Year 2016 Labor/HHS/Education Appropriations bill for the Elementary and Secondary School Counseling Program (ESSCP).

The ESSCP is the *only* authorized federal program devoted to creating and expanding counseling programs in schools. ESSCP allows schools to hire school counselors which ensure that students have access to services which support and promote optimal conditions for learning, improve school climate, improve school safety, and ultimately student learning.

The ESSCP also provides funds to school districts that demonstrate the greatest need for new or additional school counseling services, the greatest potential for replication or dissemination, or for programs that are the most innovative. The professional school counselor serves as a leader, an assertive advocate for students, consultant to families and educators, and team member to teachers, administrators and other school personnel to help each student succeed. Professional school counselors provide developmental, intervention, and remedial assistance through large and small group guidance and individual counseling activities, and crisis intervention to help all students.

The American Counseling Association is aware of the fiscal limitations facing Congress, however we urge you to recognize the cost-benefits of investing in this program. School counselors play a key role in helping students from all walks of life to develop professional and healthy attitudes in schools, which can pave the way for academic success. Such services are not only vital to underserved urban students but are even more important to students from rural areas, such as many western states and Native American reservations.



We strongly urge you to fund the ESSCP at the modest level of \$50 million dollars in order to sustain this small but very important program.

If you would like more information, please contact Guila Todd, Legislative Representative at [gtodd@counseling.org](mailto:gtodd@counseling.org). Thank you for your consideration and for your support of the Elementary and Secondary School Counseling Program (ESSCP).

Sincerely,

Richard Yep, CAE, FASAE  
Chief Executive Officer  
The American Counseling Association



Hearing on House Appropriations

Subcommittee on Labor, Health & Human Services, Education and Related Agencies

April 29, 2015

Statement for the Record

John Nash, Executive Director

The Arc of the North Carolina

**Submitted by email: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)** (Subject Line: FY 2016 written testimony for the record)

The intent of this written testimony is to express The Arc of North Carolina's strong support for continued appropriations to the Department of Health and Human Services for activities which promote community integration for individuals with disabilities.

The Arc of North Carolina is a non-profit advocacy and service organization for people with intellectual and developmental disabilities (I/DD). Founded by parents of children with disabilities sixty years ago, The Arc has a rich history of advancing policy that improves the quality of life for people with I/DD across their lifespan. With a skilled, hands-on knowledge of urban and rural needs in North Carolina, we advance our efforts through a network of chapters and direct services with a presence throughout all 100 counties.

While we believe person-centered and self-directed approaches to service delivery promote excellence and are best for all people including those with disabilities, our commitment is grounded in more than a notion of “doing the right thing.” The Arc’s experience providing quality services across the state demonstrates that services and supports uniquely tailored to an individual create a cost-effective, accountable system that is sustainable. In contrast to antiquated siloed services that often work in isolation and opposition to one another, successful modern service and supports systems prioritize integration, innovation, and choice.

The Arc requests the Subcommittee’s support for continued appropriations to the Department of Health and Human Services (HHS) for activities which promote community integration for individuals with disabilities. HHS supports a number of critical programs for full inclusion of persons with I/DD, which are widely supported and critically important to improving the lives, independence and well-being of individuals with disabilities.

We oppose efforts to prohibit the use of HHS funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is not only extremely troubling, but counter to the Supreme Court’s 1999 landmark decision in *Olmstead v. L.C.*

The nationwide trend of deinstitutionalization began decades ago, gradually turning around the tragic practice of tearing people away from their families and communities in order to provide them with services. In fact, since peaking in 1967, census reduction of institutions has occurred at an average rate of 4% nation-wide annually, resulting in the closure or in-process closure of 173 public institutions in 43 states<sup>1</sup>. This “trend” is a movement that cannot, and

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<sup>1</sup> Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., and Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities, Department of Psychiatry, and Department of Disability and Human Development, UIC.

should not, be stopped. The vast majority of people want to receive services and supports in their own homes and communities near family and friends, not in isolated institutions far from the lives and people they love and care about. In fact, Congress has a long history of oversight of institutional issues. In 1985, Senator Lowell Weicker Jr. (R-CT) chaired joint hearings<sup>2</sup> of the Senate Committee on Appropriations and the Senate Committee on Labor and Human Resources related to the “care and treatment of institutionalized mentally disabled persons” (sic) which was a precursor to the ADA which led to the 1999 Supreme Court’s decision in *Olmstead v. LC*.

In addition, rebalancing expenditures from state operated institutions to smaller community-based settings is sound economic policy. For the average cost of one individual served in a state operated institution, five persons could be served in the community. This system rebalance would assist in addressing the over 322,000 individuals with I/DD who are on a waiting list for home and community based waiver services<sup>3</sup>.

Ultimately, all people benefit when persons with disabilities, including persons with I/DD, are included in community life. People with disabilities should be welcomed and included in all aspects of our society, and like all Americans, they have a right to live in their own homes, in the community. As noted in The Arc’s most recent position statement on Housing, adopted by our Congress of Delegates in 2012, “Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with I/DD, regardless of type or severity of disability. Public policy should promote small, typical living situations for people

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<sup>2</sup> U.S. Government Printing Office (1985). Examining the Issues Related to the Care of the Nation’s Institutionalized Mentally Disabled Persons. Joint Hearings before the U.S. Senate Subcommittee on the Handicapped of the Committee on Labor and Human Resources and the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, Committee on Appropriations. Retrieved April 28, 2014 from: <http://files.eric.ed.gov/fulltext/ED263712.pdf>

<sup>3</sup> Waiting Lists for Medicaid Section 1915(c) Home and Community-Based Services Waivers <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/>

with I/DD.” In accordance with our mission, values, and positions, The Arc has long supported the Americans with Disabilities Act and its integration mandate.

The U.S. Supreme Court’s decision in *Olmstead v. LC*, 527 U.S. 581 (1999) applied the integration mandate of the Americans with Disabilities Act to state supported and operated living arrangements. The Court held that the ADA prohibits unjustified segregation of individuals with disabilities. *Olmstead* is a landmark decision in the history of the effort of people with I/DD to move out of unnecessary institutions into communities. The work of the Department of Justice (DOJ) in enforcing the *Olmstead* decision is critical and must not be undermined. This non-partisan enforcement began under President George Bush and continues under President Barack Obama.

Enforcement of the ADA’s integration mandate and the *Olmstead* decision continues to be a top priority for the disability community. The DOJ’s enforcement efforts in recent years have brought some of the most significant improvements to the lives of people with disabilities in decades. As a result, thousands of individuals with disabilities have, for the first time, been given opportunities to live in their own homes and communities, with privacy, dignity, and independence. They have been able to participate as full members of society. The DOJ’s enforcement efforts in this area have received overwhelming support from the disability community.

Neither *Olmstead* enforcement nor implementation of the Medicaid home and community-based services (HCBS) settings rules deprives anyone of the choice to live in an institution. On the contrary, *Olmstead* and the settings rules offer thousands of individuals and their families the *option* of choosing home and community-based service settings. No one is forced to move to a community setting against his or her wishes.



Inclusion of any language prohibiting use of Congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice, forcing them to live and receive services in restricted and segregated settings. We urge you to reject this language in the appropriations bill. People with disabilities have fought hard for decades for the opportunity to live, work, and receive services in integrated settings. We respectfully ask that you refrain from acting in any way which would remove community-based options.

**Written Testimony of Felice J. Levine, PhD, Executive Director  
American Educational Research Association  
U.S. House, Committee of Appropriations, Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies Fiscal Year 2016 Appropriations for the  
Institute of Education Sciences, Department of Education, April 29, 2015**

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. Appreciative of these stringent times, we recommend that the Institute of Education Sciences (IES) receive \$703.6 million in Fiscal Year 2016. This recommendation is consistent with that of the Friends of IES coalition, in which we are a leading member.

AERA is the major national scientific association of 25,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to improve education and serve the public good.

U.S. leaders and citizens broadly agree that education is a pathway to success, not just for individuals but also for our country's economy. For example, we have learned that, when looking at the bottom income quartiles, bachelor degree graduates are more upwardly mobile,<sup>i</sup> indicating that obtaining a bachelor's degree rather than only a high school diploma leads to higher lifetime earnings and lower rates of future participation in social programs.<sup>ii,iii</sup>

We also know that our citizens support investing in education. The Pew Research Center found that 60 percent of survey respondents would increase spending on education, a higher percentage than for any other category. In order, however, to allocate resources to programs and policies that work, we need reliable research to best guide decisions.

The public and policy makers value high-quality education, and our citizens are willing to spend more to improve quality; nonetheless, education research was less than 2 percent of the

\$67 billion spent on research in 2013 by institutions of higher education (largely derived from federal grants and contracts). By contrast, 56 percent of the R&D funding went to life sciences. In 2015, the budget for IES was just over 1 percent of the Department of Education budget, illustrating the underinvestment in research on education as compared with other fields.

Since IES was created in 2002, it has made dramatic contributions to the progress of education. Yet we in the U.S. have a far way to go to provide high-quality education to all of our students. In addition to old questions that remain unanswered—such as how to best prepare teachers—we have barely begun to understand the opportunities provided by advances in technology. IES needs increased funding to continue our progress, using rigorous research to inform education policy. IES comprises the four national centers listed below. Each serves a critical role in improving the quality of education in the U.S.

#### **National Center for Education Statistics (NCES)**

NCES is one of the 13 primary federal statistical agencies in the United States. It collects, analyzes, and reports on education data and statistics on the condition of education in our country; conducts long-term longitudinal studies and surveys; and supports international assessments in a manner that meets the highest methodological standards and practices for data confidentiality and data security.

Federal, state, and local policy makers rely on over two dozen NCES-supported survey programs, assessments, and administrative data sets, as do schools, educators, and researchers across the country. NCES's annual report, *The Condition of Education*, provides a comprehensive statistical overview of U.S. early childhood, K–12, and postsecondary education.

NCES also provides technical assistance to public and private education agencies and to states improving their statistical systems. Grants from the Statewide Longitudinal Data Systems

(SLDS) program encourage states to build capacity to link data between early childhood, K–12, and postsecondary systems. The President has requested doubling the amount for this program from \$35 million in FY 2015 to \$70 million in FY 2016. This would enable states and districts to conduct research and program evaluation in order to generate timely and meaningful information for improving accountability, assessment, and school support systems. One need only look at research that analyzed state administrative data in North Carolina and Washington State on early childhood programs, teacher hiring, and other timely issues to understand the value of investing in such data systems.

NCES is home to the National Assessment of Educational Progress (NAEP), known as the “Nation’s Report Card.” NAEP is an important resource for identifying long-term trends in educational proficiency in each state and—through the Trial Urban District Assessment—in the largest school districts in the nation.

Also of significance is that NCES manages the U.S. participation in international assessments and surveys, which prominently include the Program for International Student Assessment (PISA), the Trends in International Mathematics and Science Study (TIMSS), and the Progress in International Reading Literacy Study (PIRLS). Without continued adequate funding for these international assessments, it will become more difficult to accurately gauge U.S. performance in reading, math, and science in comparison to other countries. This information is particularly useful in a time of increasing global economic competition.

At the current funding level, NCES is unable to adequately fund the most timely information on several high-priority education policy issues: early childhood education, school crime and safety, and postsecondary educational costs and student progress.

**National Center for Education Research (NCER)**

Over the past decade, NCER-funded research has made significant advances in our understanding on a broad range of questions, from how best to support student learning to how to maximize school completion and adult education. One area where NCER-funded research has challenged our preconceived assumptions about education is that of teacher preparation. In the past, teacher quality was largely measured by licensure. However, additional data and rigorous research have looked at student progress, telling us much more about teacher effectiveness. Some of the results have been surprising—obtaining a master’s degree has not, for example, been linked to greater student achievement (except in one study in middle school math).

Despite the tremendous promise of NCER-funded research, in FY 2014, a quarter of proposals receiving scores of Outstanding or Excellent went unfunded. Adequate funding for NCER will allow R&D centers and research grantees to continue to produce rigorous research.

#### **National Center for Special Education Research (NCSEER)**

NCSEER supports research that investigates how to improve developmental and education outcomes for infants, toddlers, children, and youth with, or at risk of developing, disabilities. Since its creation in 2004 under the Individuals with Disabilities Education Act, NCSEER has made important contributions to research goals such as understanding factors related to children’s academic growth, developing measurement systems, documenting skill development, and developing learning and testing interventions to improve educational outcomes.

The Centers for Disease Control estimated that 1 in 68 children are identified with Autism Spectrum Disorder, a dramatic increase from the 1 in 150 children with ASD in 2002, with a corresponding increased cost of providing educational services. NCSEER leads the charge to support school-based interventions for this growing population.

Despite these important research advances that could improve the quality of life for children and families and result in enormous cost savings, NCSER was unable to fund any new research grants in FY 2014 and anticipates being unable to fund all projects receiving Excellent and Outstanding ratings in FY 2015.

#### **National Center for Education Evaluation and Regional Assistance (NCEE)**

NCEE conducts evaluations of large-scale educational projects and federal education programs and advances the use of IES knowledge by informing the public and reaching out to practitioners with a variety of dissemination strategies and technical assistance programs. The Education Resources Information Center (ERIC) is a well-used resource throughout the Department of Education, receiving 300,000 daily visitors. In addition, the What Works Clearinghouse (WWC) provides valuable information on the findings and methodologies of evaluations of various education practices and policies. Recent WWC reviews of research include studies of the Talent Transfer Initiative, college counseling during the summer after high school graduation, and the Diagnostic Assessment Tools program.

Adequate funding for IES has the potential to help with some of the other concerns of this committee. Improving the educational outcomes of our citizens would not only help to solve or prevent future labor and workforce problems but also improve the health of our citizens.

Thank you for the opportunity to submit written testimony in support of \$703.6 million for the Institute of Education Sciences in Fiscal Year 2016. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning.

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<sup>1</sup> The Pew Charitable Trusts. (2012). *Pursuing the American Dream: Economic Mobility Across Generations*. Washington, DC: Author.

<sup>2</sup> Carnevale, A. P., Rose, J., & Cheah, B. (2011). *The College Payoff*. Washington, DC: Georgetown Center on Education and the Workforce.

<sup>3</sup> Baum, S., Ma, J., & Payea, K. (2013). *Education Pays 2013: The Benefits of Higher Education for Individuals and Society*. Washington, DC: The College Board.



**HEALTH**  
HEARTLAND HEALTH OUTREACH, INC.

**Testimony Prepared by Deborah Hinde, Chief Development Officer of Heartland Health Outreach, Inc. for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive in achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the effects of the HIV Treatment Cascade.

Heartland Health Outreach, Inc. is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide nutritious, medically appropriate food for more than 410,000 meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

#### **1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified

the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public



insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more

expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

### **Conclusion**

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare

resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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<sup>1</sup> Aidala A., Yomogida M., Vardy Y. & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)

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<sup>3</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

<sup>4</sup> Ibid.

<sup>5</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

<sup>6</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

- <sup>139</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, *J Prim Care Community Health*, 4(4):311-7 (June 3, 2013)
- <sup>140</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, *J Prim Care Community Health*, 4(4):311-7 (June 3, 2013)
- <sup>141</sup> Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc*. 1998; 98: 434-438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition*. 1999; 18(6): 371-374.
- <sup>142</sup> M. S. Cohen *et al.*, "Prevention of HIV-1 Infection with Early Antiretroviral Therapy," *N. Engl. J. Med.* **365**, 493-505 (2011). HPTN 052
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- <sup>145</sup> Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med*. 2009 Jan;24(1):14-20. doi: 10.1007/s11606-008-0824-5. Epub 2008 Oct 25.

April 29, 2015



The Honorable Tom Cole (OK-4)  
Labor, Health and Human Services, Education,  
and Related Agencies Subcommittee  
Committee on Appropriations  
U.S. House of Representatives  
[LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)

**VIA ELECTRONIC MAIL**

**Testimony of Vicki Smith, Executive Director  
Disability Rights North Carolina**

Disability Rights NC is North Carolina's federally mandated protection and advocacy organization. We work to protect the legal rights of North Carolinians with disabilities. We are an independent, non-profit 501(c)(3) legal organization with 38 employees, including 16 licensed attorneys representing clients in a broad range of matters related to their disabilities, including employment, education, housing, abuse, health care matters, and community access. We welcome the opportunity to provide written testimony of how we respond to the requests for legal assistance we field from individuals with disabilities in North Carolina.

Since 2008, we have been the organization designated by North Carolina to receive funds administered under various federal statutes for the "protection and advocacy" of people with disabilities, including specific funding designated to serve individuals with developmental disabilities (i.e. "PAIDD" funds). PAIDD funds were first made available with the passage of the Developmental Disabilities Assistance and Bill of Rights Act of 1975. With these funds, we monitor and investigate complaints of abuse and neglect, in both institutional and community settings, and protect the legal rights of North Carolinians with intellectual and developmental disabilities.

*North Carolina's Protection  
and Advocacy System*

3724 National Drive  
Suite 100  
Raleigh, NC 27612

919-856-2195 [www.disabilityrightsnnc.org](http://www.disabilityrightsnnc.org)  
877-235-4210  
888-268-5535 TTY  
919-856-2244 fax

In 2014, Disability Rights North Carolina used its PAIDD funding to:

- Investigate 10 allegations of abuse, neglect, and/or death in state-operated or state-licensed facilities;
- Conduct 84 monitoring visits to review living, working, and other conditions in segregated settings, including regular visits to 4 intermediate care facilities for the mentally retarded, 4 state-operated developmental disability centers, 2 state-operated schools for the deaf, and 2 state-operated neuromedical facilities, all of which serve people with developmental disabilities;
- Provide 319 individuals with information, technical assistance and referral services regarding civil, human and legal rights;
- Represent or provide self-advocacy assistance to 106 individuals with intellectual or developmental disabilities regarding access to housing, education, employment, and the community; and
- Co-counsel in two systemic lawsuits regarding funding medically necessary health care options in the community for Medicaid-waiver recipients with intellectual and developmental disabilities.

These numbers account for our work but they are inadequate to fully to describe it. For example, because of our advocacy efforts while monitoring at a developmental center, a national expert on Trauma Informed Care provided a daylong training to staff on trauma, its causes, behaviors that can be associated with it, and appropriate behavioral interventions. After an advocate expressed serious concern during a

developmental center's Human Rights Committee meeting, the center has agreed to review its use of an illegal restraint in behavior support plans.

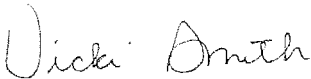
In 2014, Disability Rights North Carolina received and reviewed 62 reports of deaths of individuals with an intellectual or developmental disability residing in a state-licensed facility; of these 62 reports, 2 of the deaths were suspicious and investigated. Because of our experiences representing people without natural support from family members our organization was invited and presented testimony on the experience of individuals with public guardians to a legislative oversight subcommittee. We provided recommendations for improving the state's guardianship laws and their implementation.

In cases where we advocated on behalf of students, corrective action plans have been put into place requiring countywide notification of proper IEP procedures and training for a variety of staff. Through individual client representation and discussions with policy makers, our staff has continually advocated for children whose treatment at residential settings is terminated by Medicaid managed care organizations, even though no proper community discharge plan is in place to continue necessary treatment. We believe this work contributes significantly to the safety, well-being, and independence of people with intellectual and developmental disabilities in North Carolina.

Thank you for taking the time to understand our organization and for this opportunity to submit testimony. We hope you understand how important our funding is to the individuals with intellectual and developmental disabilities living in North Carolina. Please know that Disability Rights NC is a resource for your constituent services and add our contact information to your referral list. If your office receives calls

from people with disabilities (including people with sensory disabilities, mental illness, and traumatic brain injuries) who have been denied services or experience discrimination based on disability, please consider suggesting they contact us. We welcome the opportunity to discuss the legal matters facing individuals with disabilities further with the committee or its staff. Please do not hesitate to contact me at (919) 856-2195 or [vicki.smith@disabilityrightsnnc.org](mailto:vicki.smith@disabilityrightsnnc.org) if you would like to learn more about Disability Rights North Carolina and our work on behalf of people with disabilities.

Sincerely,

A handwritten signature in black ink that reads "Vicki Smith". The script is cursive and fluid, with the first name "Vicki" and last name "Smith" clearly distinguishable.

Vicki Smith  
Executive Director





**Testimony Prepared by Matthew Pieper, Executive Director of Open Hand Atlanta for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Open Hand Atlanta is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 240,000 medically tailored, home delivered meals annually to people living with HIV/AIDS. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

## **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a

control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

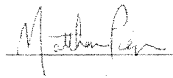
## Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



Matthew Pieper  
Executive Director  
Open Hand Atlanta  
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Atlanta, GA 30324  
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- <sup>1</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheets.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheets.pdf)
- <sup>2</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.
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- <sup>6</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).
- <sup>7</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, *J Prim Care Community Health*, 4(4):311-7 (June 3, 2013)
- <sup>8</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, *J Prim Care Community Health*, 4(4):311-7 (June 3, 2013)
- <sup>9</sup> Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. *J Am Diet Assoc.* 1998; 98: 434-438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. *Clinical Nutrition.* 1999; 18(6): 371-374.
- <sup>10</sup> M. S. Cohen *et al.*, "Prevention of HIV-1 Infection with Early Antiretroviral Therapy," *N. Engl. J. Med.* **365**, 493-505 (2011). HPTN 052
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**Testimony of Stephen C. Shannon, D.O., M.P.H.  
President and Chief Executive Officer  
American Association of Colleges of Osteopathic Medicine**

**Concerning the Department of  
Health and Human Services Appropriations for Fiscal Year 2016**  
*Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and  
Human Services, Education, and Related Agencies*  
April 29, 2015

**The American Association of Colleges of Osteopathic Medicine (AACOM) strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to \$7.48 billion; funding for key priorities in HRSA's Title VII programs under the Public Health Service Act (minimum of \$71 million for the Primary Care Training and Enhancement (PCTE) Program; \$4 million for the Rural Physician Training Grants; \$25 million for the Centers of Excellence (COE); \$14.2 million for the Health Careers Opportunity Program (HCOP); \$46 million for the Scholarships for Disadvantaged Students (SDS) Program; \$34.2 million for the Geriatric Education Centers (GECs); and \$75 million for the Area Health Education Centers (AHECs); long-term sustainable funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; sustainment of the National Health Service Corps (NHSC) and other scholarship and loan repayment programs; \$32 billion for the National Institutes of Health (NIH); and \$375 million in base discretionary funding for the Agency for Healthcare Research and Quality (AHRQ).**

AACOM represents the 31 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 45 teaching locations in 30 states. In the 2014-15 academic year, these colleges are educating over 24,600 future physicians – more than 25 percent of new U.S. medical students.

**The Title VII health professions education programs**, authorized under the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the health care workforce, acting as an essential part of the health care safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII programs are the only federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

As the demand for health professionals increases in the face of impending shortages, combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile health care system. AACOM appreciates the investments that have been made in these programs, and we urge the Subcommittee to include support for the following programs: **the PCTE Program, the Rural Physician Training Grants, the COE, the HCOP, the SDS Program, the GECs, and the AHECs.**

The **PCTE Program** provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. **AACOM supports a minimum of \$71 million, a \$20 million increase above the \$51 million in the President's FY13 budget and a necessary increase over the FY15 budget request of \$37 million, to allow for a competitive grant cycle for the PCTE Program's physician training and development.**

The **Rural Physician Training Grants** will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to



attract and maintain well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. **AACOM supports the President's FY16 budget request of \$4 million for the Rural Physician Training Grants.**

The **COE Program** is integral to increasing the number of minority youth who pursue careers in the health professions. **AACOM supports the President's FY16 budget request of \$25 million for the COE Program.**

The **HCOP** provides students from disadvantaged backgrounds with the opportunity to develop the skills needed to successfully compete, enter, and graduate from health professions schools. **AACOM supports an appropriation of \$14.2 million for HCOP, which would continue the FY15 enacted level.**

The **SDS Program** provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities. **AACOM supports level funding of \$46 million for the SDS Program.**

**GECs** are collaborative arrangements between health professions schools and health care facilities that provide the training of health professions students, faculty, and practitioners in the diagnosis, treatment, prevention of disease, disability, and other health issues. **AACOM supports the President's FY16 budget request of \$34.2 million for the GECs.**

The **AHEC Program** provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders work to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the health care services delivery system, specifically in rural and underserved areas. **AACOM supports an appropriation of \$75**

**million for the AHEC Program in FY16 and strongly opposes the elimination of this vital program in the President's FY16 budget.**

AACOM has concerns with the Administration's budget request that would cut nearly \$16 billion from Medicare GME. Because GME funding is critical to medical residency training across the country, an imperative juncture of the development of the future health care workforce, AACOM believes that current GME funding should not be eliminated and simply shifted into other relevant health care workforce programs. Instead, additional investments in GME are critical to an already insufficiently-funded system.

AACOM continues to strongly support the sustainment of the **THCGME Program**, which provides funding to support primary care medical and dental residents training in community-based settings. THCs currently train more than 550 medical and dental residents and are providing more than 700,000 primary care visits in underserved rural and urban communities. This program will also provide long-term benefits. According to HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas as physicians who train in other settings. **We are pleased to see a two-year extension of this program in the *Medicare Access and CHIP Reauthorization Act of 2015* (Public Law No: 114-10). We will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation of this successful program beyond FY17. In addition, we support an investment of \$10 million minimally in FY16 for THC development grants.**

The **NHSC** supports physicians and other health professionals who practice in health professional shortage areas across the U.S. In FY14, the NHSC had a total of 9,242 primary care clinicians providing health care services. The NHSC projects that a field strength of

15,000 primary care clinicians will be in health professional shortage areas in FY16. In addition, more than 1,100 students, residents, and health providers receive scholarships or participate in the Student to Service Loan Repayment Program to prepare to practice. Of the new NHSC scholarships and loan repayment awarded to students (D.O. and M.D.) in FY14, 30 percent were awarded to D.O.s. **We are pleased to see a two-year extension of this program in the *Medicare Access and CHIP Reauthorization Act of 2015* (Public Law No: 114-10). AACOM supports the continuation and sustainability of this critical program beyond FY17.**

Research funded by the **NIH** leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our nation's health and save lives. To maintain a robust research agenda, further investment will be needed. **AACOM recommends \$32 billion for the NIH.**

**AHRQ** supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our nation's health and health care. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. **AACOM recommends \$375 million in base discretionary funding, restoring the base to FY 2011 levels for the AHRQ.** This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

Contact: Maggie Elehwany  
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 Government Affairs and Policy  
 National Rural Health Association

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Testimony of the National Rural Health Association (NRHA)  
 Concerning HRSA's Programs Impacting Rural Health  
*Submitted for the Record to the House Committee on Appropriations Subcommittee  
 on Labor, Health and Human Services, Education and Related Agencies – FY 2016*

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2016 funding levels for programs with a significant impact on the health of rural Americans.

NRHA is a national nonprofit membership organization with a diverse collection of 21,000 individuals and organizations who share a common interest in rural health. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research.

NRHA is advocating support for a group of rural health program that assist rural communities in maintaining and building a strong health care delivery system into the future. Most importantly, these programs help increase the capacity of the rural health care delivery system and true safety net providers. Rural Americans, on average, are poorer, sicker and older than their urban counterparts. Programs in the rural health safety net increase access to health care, help communities create new health programs for those in need and train the future health professionals that will care for the 62 million rural Americans. With modest investments, these programs evaluate, study and implement quality improvement programs and health information technology systems.

Important rural health programs supported by NRHA are outlined below.

**Rural Health Outreach and Network Grants** provide capital investment for planning and launching innovative projects in rural communities that will become self-sufficient. These

grants are unique federal grants in that they allow a great deal of flexibility for the community to build a program around their community's specific needs. Grant funds are awarded for communities to develop needed formal, integrated networks of providers that deliver primary and acute care services. The grants have led to successful projects including information technology networks, oral screenings, and preventative care. Due to the community nature of the grants and the focus on sustainability after the grant term has run out – 85 percent of the grantees continue to deliver services a full five years after federal funding ends. Request: \$70 million.

**Rural Health Research and Policy Grants** form the federal infrastructure for rural health policy. These grants provide policy makers with policy-relevant research on problems facing rural communities in providing access to quality affordable care and to improving population health in rural America. By funding rural health research centers across the country These grants fund, these grants produce a mix of health services research, epidemiology, public health, geography, medicine, and mental health. These funds allow rural America to have a coordinated voice in the Department of Health and Human Services (HHS), in addition to providing expertise to agencies such as the Centers for Medicare and Medicaid Services. As a part of this request, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the state rural health associations. Request: \$11.3 million.

**State Offices of Rural Health** provide state specific infrastructure for rural health policy. These state offices are the counterpart to the federal rural health research and policy framework. State offices form an essential link between small rural communities and the state and federal resources to develop long term solutions to rural health problems. These funds provide necessary capacity to states for the administration of critical rural health programs, assist

in strengthening rural health care delivery systems, and maintaining rural health as a focal point within each state. The state offices play a key role in assisting rural health clinics, community health centers, and small, rural hospitals assess community health care needs. This program creates a state focus for rural health interests, brings technical assistance to rural areas, and helps frontier communities tap state and national resources available for health care and economic development. State offices form an essential connection to other state agencies and local communities; allowing federal resources to best address the unique needs of rural communities. Request: \$15 million.

**Rural Hospital Flexibility Grants** fund quality improvement and emergency medical service projects at Critical Access Hospitals (CAHs). These grants allow rural communities to improve access to care, develop increased efficiencies, and improved quality of care by leveraging the services of CAHs, Emergency Medical Services (EMS), clinics, and health practitioners. These grants serve an important function in increasing information technology activities in rural America. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to improve business operations, focus on quality improvement, and ensure compliance with health information privacy regulations. Request: \$49.2 million.

**Rural and Community Access to Emergency Devices Grants** help communities afford the purchase of emergency devices, such as defibrillators, and the necessary training for community members and first responders in the proper use of these devices. The proper and timely use of a defibrillator following a sudden cardiac arrest doubles a victim's chance of survival. Placement of devices within the community where cardiac arrest is likely to occur allows for greater success. Such immediate intervention are particularly important in rural

America where follow on medical care may require longer wait times due to long distances to a hospital, mountainous terrain, or inclement weather. Request: \$4.5 million.

**The Office for the Advancement of Telehealth (OAT)** supports the provision of clinical services at a distance, reduces rural provider isolation, fosters integrated delivery systems through network development, and tests a broad range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, save money by reducing unnecessary office visits and hospital stays, and provide continuing education to isolated rural providers. The OAT coordinates and promotes the use of telehealth technologies by fostering partnerships between federal and state agencies and private sector groups. Since telehealth is still an emerging field with new approaches and technologies; continued investment in the infrastructure and development is needed. Request: \$16.8 million.

**Title VII Health Professions Training Programs (with a significant rural focus):**

- **Area Health Education and Centers (AHECs)** encourage and provide financial support to those training to become health care professionals in rural areas. Without this experience and support in medical school, far fewer professionals would be aware of the needs of rural communities and even fewer would make the commitment to practice in rural areas. AHECs support the recruitment and retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas. It has been estimated that nearly half of AHECs would shut down without federal funding, placing future access to health care in rural communities at risk. Request: \$82.5 million.

- **Rural Physician Pipeline Grants** help medical colleges develop rural specific curriculum and to recruit students from rural communities that are likely to return to their home

regions to practice. This "grow-your-own" approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. Request: \$4.8 million.

- **Geriatric Programs** train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality health care for seniors. Rural America has a disproportionate share of our nation's elderly and is more likely to have physician shortages than urban locations. Without this program, rural health care provider shortages would grow. Request: \$40.4 million.

The National Rural Health Association appreciates the opportunity to provide our recommendations to the Subcommittee. These programs are critical to the rural health delivery system and help maintain access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of the Subcommittee to continue making these important investments in rural health.



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**Testimony of the Association for Professionals in Infection Control and Epidemiology (APIC) and**

**The Society for Healthcare Epidemiology of America (SHEA)**

**to the U.S. House of Representatives Appropriations Subcommittee on**

**Labor, Health and Human Services, Education and Related Agencies on**

**Fiscal Year 2016 Appropriations for the U.S. Department of Health and Human Services (HHS)**

**April 28, 2015**

The Association for Professionals in Infection Control and Epidemiology (APIC) and the Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs: Within the Centers for Disease Control and Prevention (CDC) National Center for Emerging and Zoonotic Infectious Diseases: **\$32 million for the National Healthcare Safety Network (NHSN), \$501 million for Core Infectious Diseases including \$264 million for the new Antibiotic Resistance Solutions initiative, and \$30 million for the Advanced Molecular Detection (AMD) Initiative.** Additionally, we request **\$34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and \$4.6 billion for the**

**National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID).**

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 25 hospitalized patients has an HAI, totaling approximately 722,000 infections and 75,000 deaths in 2011. Further, a growing number of infections are resistant to antibiotics causing an estimated two million illnesses and approximately 23,000 deaths annually. Antibiotics, created to save lives, are now contributing to patient deaths through misuse and overprescribing that promotes the emergence of highly resistant bacteria and leads to deadly adverse events. AR is one of the most critical public health and patient safety threats facing our nation. The actions we take now will determine if we will return to an era where even a small cut could prove fatal.

**Centers for Disease Control and Prevention (CDC)**

**We urge you to support \$32 million for CDC's National Healthcare Safety Network (NHSN) and Prevention Epicenters Program.** This request represents a \$14 million increase over the FY 2015 enacted level for the NHSN to support HAI prevention and reporting efforts for more than 17,000 healthcare facilities across the spectrum of care. It will also enable CDC to conduct applied research on interventions for infection prevention and continue to provide data for national HAI elimination goals and targeted HAI prevention initiatives. This funding level will allow for the extension and implementation of the NHSN Antimicrobial Use and Resistance Module to track antibiotic use in healthcare settings and provide real time data about antibiotic use and trends.

NHSN data and the Prevention Epicenters Program, a collaboration between CDC and academic medical centers that conduct innovative infection prevention and control research, serve as the foundation for the development of pioneering, evidence-based HAI prevention strategies. Consistent, scientifically sound data reported at the state and federal level are necessary to support transparency to the public, allowing for equitable comparisons between facilities, as well as ensure that accurate data are available to evaluate progress related to the National Action Plan to Prevent HAIs.

Since 2008, the cumulative impact of CDC infection prevention resources, guidelines and programs has contributed to significant reductions of HAIs in healthcare settings, including a 44% reduction in central line-associated bloodstream infections, a 31% reduction in healthcare-associated invasive MRSA infections, and a 20% reduction in surgical site infections.

Despite these improvements to patient safety, the significant increase in facility users, and the importance of the system's contributions to reducing HAIs and combating AR, funding for NHSN and the Prevention Epicenters has been flat since FY 2010.

**APIC and SHEA request \$501 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antibiotic Resistance, and Emerging Infections Program.** The Emerging Infections Program (EIP) helps states, localities and territories in detecting and protecting the public from known infectious disease threats in their communities while maintaining our nation's capacity to identify new threats as they emerge. Increased funding for Core Infectious Diseases will expand the number of EIP sites from 10 to 20.

**We support the \$264 million request in the President's budget for the Antibiotic Resistance Solutions Initiative.** This comprehensive initiative will establish state AR prevention programs in all 50 states and 10 large cities to protect patients and communities through the rapid identification of outbreaks. The initiative will improve response time to outbreaks of infectious disease threats by creating a network of AR regional labs that use cutting edge methods to track and mitigate disease spread. The AR Solutions Initiative will incorporate NHSN antibiotic use information to improve antibiotic prescribing practices, which contributes to the rise of resistant pathogens. Moreover, we strongly support CDC's focus on the implementation of antibiotic stewardship programs in all healthcare settings. The initiative anticipates outcomes resulting in a reduction of carbapenem-resistant Enterobacteriaceae (CRE) and *Clostridium difficile*, two pathogen groups labeled as urgent threats by CDC in 2013, by 60% and 50% respectively.

**We urge your continued support of the President's \$30 million request for the Advanced Molecular Detection (AMD) Initiative** in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This initiative is critical because it strengthens CDC's epidemiologic and laboratory expertise to effectively guide public health action.

**Agency for Healthcare Research and Quality (AHRQ)**

**We request your support of the proposed investment of \$34 million for AHRQ's HAI research activity.** These grants (\$17.8 million) and contracts (\$16.2 million) will advance our knowledge about effective approaches to reducing HAIs while promoting the

implementation of proven methods for preventing HAIs. In addition, contracts funded by the HAI budget will accelerate the nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP), an evidence-based safety framework for improvement in culture, teamwork, communication, and patient-care practices.

**National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID)**

**APIC and SHEA support the \$4.6 billion requested by the Administration for FY 2016 for the National Institute of Allergy and Infectious Diseases (NIAID) within NIH.**

The emergence of diseases like Ebola illustrate the need for critical research that can lead to the discovery of new therapies, new diagnostic approaches, and new preventative strategies. NIAID's long-standing basic and translational research on Ebola and other hemorrhagic fever viruses has yielded some of today's most promising therapeutic candidates. Additionally, NIAID is addressing the growing problem of antimicrobial resistance (AR) through basic research to understand how microbes acquire and transmit resistance genes and clinical efforts including studies to optimize the use of currently licensed drugs, combination therapies, and alternative, non-antibiotic treatment strategies.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs, combat antibiotic resistance and improve patient safety and outcomes.

**About APIC:** APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 15,000 members direct and maintain infection prevention programs that prevent suffering, save lives and contribute to cost savings for hospitals and other healthcare facilities.

**About SHEA:** SHEA is a professional society representing more than 2,000 physicians and other healthcare professionals globally that have expertise in and passion for healthcare epidemiology and infection prevention. SHEA's mission is to prevent and control healthcare-associated infections and advance the field of healthcare epidemiology.

Jared Frost, Senior Associate, Legislative Affairs  
American College of Physicians

**Statement for the Record of the American College of Physicians to the  
House Appropriations Subcommittee on Labor, Health and Human Services,  
Education, and Related Agencies  
Re: FY2016 Appropriations, Department of Health and Human Services  
April 28, 2015**

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for FY2016. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 141,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for FY2016, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement, at no less than \$71 million;
- National Health Service Corps, \$810 million in total program funding, including at least \$287.4 million through discretionary appropriations;
- National Health Care Workforce Commission, \$3 million;
- Agency for Healthcare Research and Quality, \$375 million.

The United States is facing a shortage of physicians in key specialties, notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), the Congressional Budget Office has estimated, as of March 2015, the demand for primary care services will increase with the addition of 25 million Americans receiving access to health insurance, including an additional 14 million under Medicaid/CHIP, once the law is fully implemented. With increased demand, current projections indicate there will be a shortage of 12,500 to 31,100 primary care physicians by 2025. (IHS Inc., prepared for the Association of American Medical Colleges. *The Complexities of Physician Supply and Demand: Projections from 2013 to 2025*. March 2015. Accessed at:

<https://www.aamc.org/download/426260/data/physiciansupplyanddemandthrough2025keyfindings.pdf>). Without critical funding for vital workforce programs, this physician shortage will

only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with **over 100 studies showing primary care is associated with better outcomes and lower costs of care**

([http://www.acponline.org/advocacy/where\\_we\\_stand/policy/primary\\_shortage.pdf](http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf)).

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health

professionals not met by traditional market forces, and are critical in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the **Section 747, Primary Care Training and Enhancement** program at \$71 million, in order to maintain and expand the pipeline for individuals training in primary care. The Section 747 program is the only source of federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists. Without a substantial increase in funding, for the fifth year in a row, HRSA will not be able to carry out a competitive grant cycle for physician training; the nation needs new initiatives supporting expanded training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges \$810 million in total program funding for the **National Health Service Corps** (NHSC), as requested in the President's FY2016 budget; this amount includes \$287.4 million in discretionary spending through new budget authority and \$522.63 million in new mandatory funding. Since the enactment of the ACA, the NHSC has awarded over \$1 billion in scholarships and loan repayment to health care professionals to help expand the country's primary care workforce and meet the health care needs of underserved communities across the country. With a field strength of over 9,000 primary-care clinicians, NHSC members are providing



culturally competent care to almost 10 million patients at nearly 15,000 NHSC-approved health care sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to 15,000 and would serve the needs of more than 16 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with increased appropriations, they can do more. For FY2016, the NHSC's funding situation was particularly urgent and faced a funding cliff because its mandatory funding was set to expire and with no current budget authority. The College was therefore pleased that the recently-passed *Medicare Access and CHIP Reauthorization Act*, H.R. 2, continued the NHSC at its FY2015 funding level for FY2016 and FY2017 (through an extension of mandatory resources). However, ACP believes that the Corps also needs discretionary funding to continue and expand its mission.

We urge the Subcommittee to fully fund the **National Health Care Workforce Commission**, as authorized by the ACA, at \$3 million. The Commission is authorized to review current and projected health care workforce supply and demand and make recommendations to Congress and the Administration regarding national health care workforce priorities, goals, and policies. Members of the Commission have been appointed, but have not begun work due to a lack of funding. The College believes the nation needs a comprehensive workforce policy founded on sound research to determine the nation's current and future needs for physicians by specialty and geographic areas; the work of the Commission is imperative, now more than ever, to ensure Congress is creating the best policies for our nation's needs.

The **Agency for Healthcare Research and Quality** (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed health care decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and recommends a budget of \$375 million. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, help transform health and health care.

In conclusion, the College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance health care system and build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you begin to work on the FY2016 appropriations process.

**Randella Bluehouse**  
**Executive Director**  
**National Indian Council on Aging (NICOA)**

Chairman Cole, Ranking Member DeLauro;

On behalf of the National Indian Council on Aging (NICOA), the only national organization dedicated to the well-being of American Indian and Alaskan Native Elders, we thank you for the opportunity to submit testimony in support of the Department of Health and Human Services' proposed increase of \$2.9 million for the Older Americans Act Title VI American Indian senior nutrition programs, as well as the Department of Labor's proposed funding for the Older Americans Act Title V Community Services Employment for Older Americans program (also known as SCSEP).

American Indians and Alaskan Natives are more likely to live in poverty in their old age. Title VI is an example of a lack of parity between states and tribal organizations. According to the 2010 Census, the American Indian/Alaskan Native population increased at a rate faster than the total population, rising from 4.1 million to 5.2 million. Yet, the funding for Title VI nutrition and supportive services programs has continually decreased since FY 2011, though Title VI recipients are supposed to receive "comparable services" according to the Older Americans Act.

Under the Older Americans Act, Native American nutrition and supportive services are funded by grants awarded under Title VI to Indian tribal organizations, Alaskan Native organizations and non-profit groups representing Native Hawaiians. These grants were awarded to 264 tribal organizations and 1 Native Hawaiian organization in FY 2014.

As an organization which works on a daily basis with older American Indians/Alaskan Natives, we see the increasing need for these services as the population grows. These services, like the Title III services that states receive, help delay costly nursing home care and allow American Indians/Alaskan Natives to remain at home, in the community, and/or on the reservation, even if they have limitations on their activities of daily living. According to the Administration for Community Living's Congressional Justification, the FY 2016 request level will provide 620,000 rides, 2.9 million meals at home, and 2.5 million meals at congregate sites to over 74,000 American Indian/Alaskan Native elders.

We also provide our support for Title V of the Older Americans Act, the Community Services Employment for Older Americans program (also known as SCSEP). We are proud to serve as a national contractor for the program, operating in fourteen states. We are pleased that the President's budget this year does not recommend cutting the program as it has recommended in prior years. In this time of high unemployment for older adults, we hope that you continue funding the one program that is specifically targeted toward low-income older workers at the \$434.4 million level from FY 2014 and FY 2015, if not consider an increase.

We are also pleased that the President's budget does not recommend transferring the program from the Department of Labor to the Department of Health and Human Services. We believe it

operates well under the Department of Labor and does not need to be transferred as has been proposed in prior years.

As the American Indian/Alaskan Native population ages, now is the time to provide funding for their nutrition and supportive services. We hope you will consider the President's request as a modest but necessary increase for these much-needed programs.

Thank you for your past and future support.

**Robert Blancato**  
**National Coordinator**  
**Elder Justice Coalition**

Chairman Cole, Ranking Member DeLauro;

On behalf of the bipartisan Elder Justice Coalition and its 3,000 members, we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed \$25 million funding for the Elder Justice Act within the Administration for Community Living.

Our topic has been and must always be a bipartisan issue: preventing elder abuse, neglect and exploitation. We ask this Subcommittee to provide this funding in a bipartisan fashion as part of the solution to the national disgrace of elder abuse.

Elder abuse is a large and growing problem in our society. According to Department of Justice figures, there are more than six million victims of elder abuse per year; roughly one of every ten persons over 60 will end up a victim of elder abuse. However, a New York State study found for every elder abuse case known to agencies, twenty-four were unreported. Victims of elder financial abuse lose an estimated \$2.9 billion per year, which can include entire life savings. A new study published by True Link Financial found that the problem of financial exploitation may be as great as \$36 billion per year. One-half of those with dementia will fall victim to elder abuse, neglect and/or exploitation. In short, the situation is dire.

The Elder Justice Act, passed in 2010, would address these problems. The Act, if funded, would strengthen the State Long-Term Care Ombudsmen Program. It would provide for the development of forensic centers to study the problem of abuse and how we can better detect abuse and potential abusers. It would also enhance and train long-term care staffing in facilities.

Funding for the Elder Justice Act has not been made in order to fulfill the provisions of the Act. We are very grateful for the first-time funding the Appropriations Committee made last year for the Act in the amount of \$4 million, but the Act needs more of an investment in order to fulfill its potential. This is why we support funding for the Act at the proposed \$25 million level.

The funding request includes:

- \$15 million for additional demonstration grants to expand participation in the National Adult Maltreatment Reporting System (NAMRS, a national APS data collection system) to up to 15 additional states, bringing approximately 45% of the 56 APS jurisdictions online in the second year of implementation. (The FY 2015 funding is being distributed through competitive grants to approximately ten states.)
- \$3 million to operate, maintain, and provide technical assistance to the NAMRS system.
- \$3.25 million to analyze and evaluate APS services nationwide for effectiveness, evidence-based and best practices, continuing work begun in FY 2015.

- \$3 million for research into screening for elder abuse, neglect and exploitation, and foundational research.
- \$0.75 million for program implementation and oversight.

Data collection is essential to understanding and preventing elder abuse. Other forms of crime, such as child abuse, have standardized national databases. The National Child Abuse and Neglect Data System (NCANDS) database has been in existence since 1998. This allows states to more easily discover trends and researchers to learn about perpetrators and victims. Further, a lack of data has hurt the elder justice community's efforts to call awareness to the problem of elder abuse and to compete effectively for resources in an era where data often drives dollars. Continuing the work started in FY 2013 with the Prevention and Public Health Fund money which established NAMRS and continued with the \$4 million appropriated in FY 2015 is vital for consistency in the field.

The Coalition also supports the evaluation and analysis of APS programs using an evidence-based approach and best practices. To be effective, APS programs must have consistency and high quality nationally. Elder abuse happens in all states and congressional districts, and in some cases, elder abuse happens across county and state lines. Thus, having uniform best practices is key to ensuring that victims receive uniform services.

Research in the elder abuse field, like data collection, is desperately needed. Money has never been specifically appropriated for research; the limited resources the field has go straight into assisting victims. However, victims can be more appropriately—and cost-effectively—assisted if they are identified early via effective screening. A great deal of trauma can be prevented with effective screening. Thus, research into how to screen accurately is exceedingly important.

This increased investment of \$25 million would mean that current federal and state resources could be used more effectively while also responding to elder abuse systematically. For these reasons as well as the potential of lowering rates of future victimization the investment would provide a solid return on investment.

This is an investment because, according to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed \$5 billion annually. Since these victims are older adults, Medicare and Medicaid bear the bulk of these costs. Other federal programs may end up paying for elder abuse victims, including income support programs, because financial abuse victims who were once self-supporting may lose everything in one scam. We can begin to save money for the federal government if we make this relatively small investment today.

We also support maintaining, if not increasing, the amount of money available for Social Services Block Grant programs, which in addition to providing APS funding, also provides important funding for supportive services available to elder abuse victims. APS is primarily funded through optional state distributions from their Social Services Block Grant allotment; only 37 states provide any additional federal funding for their federal APS programs.

Elder abuse victims can be household names like the late Mickey Rooney, Brooke Astor, or Casey Kasem. We offer our testimony for them today but also for those who are not known to the public. The people you have never heard of, the stories that don't even make the local news, are the ones who need a voice that can be heard in this testimony.

Since the Elder Justice Act has many more important provisions that are not funded in this proposal, please view this \$25 million as a floor to build on, and not a ceiling. We look forward to working with you to ensure that this elder justice appropriation provides us with the best possible return on investment and outcomes.

Thank you for your past and future support.

**Ann Cooper, Chair**  
**Robert Blancato, Executive Director**  
**National Association of Nutrition and Aging Services Programs (NANASP)**

Chairman Cole, Ranking Member DeLauro;

On behalf of the National Association of Nutrition and Aging Services Programs (NANASP), an 1,100-member nonpartisan, nonprofit, membership organization for national advocates for senior health and well-being, we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of \$59.9 million for Older Americans Act Title III(C) senior nutrition programs within the Administration for Community Living.

Older Americans Act congregate and home-delivered meals programs are provided in every state and congressional district in this nation. Approximately 2.4 million seniors in 2014 received these services. As the Administration for Community Living (ACL) Congressional Justification states, studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. Thus, these meal recipients are able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

In addition, for participants in the congregate program in particular, the nutrition programs provide a daily opportunity for socialization, preventing isolation and promoting health and wellness. For home-delivered meals recipients, their delivery driver may be the only person they see all day—this wellness check is also key to their health.

In FY 2014 and FY 2015, Older Americans Act Title III(C) programs received appropriations in the amount of \$814.6 million. Though we are thankful that this represents an increase from FY 2013, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing.

The President's FY 2016 funding request includes:

- \$39.9 million for congregate and home-delivered meals
- \$20 million for evidence-based demonstration grants

The additional \$39.9 million for congregate and home-delivered meals would allow ACL to maintain the total number of meals projected to be provided in FY 2015. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services. As we saw in FY 2013 when sequestration was in effect, our programs had lengthy wait lists and some sites even closed for lack of funding. One program created its first wait list in over 90 years of operation. We cannot afford to continue to backslide, especially as another round of sequestration looms on the horizon.



Further, these services are designed to target those in the “greatest social and economic need,” according to the Older Americans Act and to actual practice in the field. According to ACL studies, approximately two-thirds of home-delivered meal recipients have annual incomes of \$20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about nine percent of low-income older adults are even receiving meals services. For a small investment, more at-risk older adults could receive nutritious meals.

NANASP also supports evidence-based demonstration grants for senior nutrition programs. It is important that programs be as modern as possible and that all funds that these programs have are spent effectively and wisely. Many programs are already using innovative and cost-effective practices; they just need to be expanded and replicated at the national level. Further, it is important to ensure that programs are ready to meet the demands of the boomer population aging into services as caregivers and recipients who are accustomed to different ways of interacting with providers, such as “apps,” Facebook, and websites.

Investing in these programs would be cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older adults have hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy meals, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Data from ACL's National Survey of Older Americans Act Participants shows that congregate and home-delivered meals recipients are significantly less healthy than older adults in general. About 57 percent of congregate and 72 percent of home-delivered recipients have five or more chronic conditions. About 32 percent of congregate and 51 percent of home-delivered recipients take over six medications per day and some take as many as 30 medications.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the health care system.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. A senior can be fed for a year for about \$1,300. This \$1,300 is the same as the cost of a week in a nursing home or one day in the hospital. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves \$50.

For over forty years, the Older Americans Act nutrition programs have been serving older adults who are frail, isolated, and in great need of assistance. With more than 10,000 seniors turning 65 every day, now is the time to provide a greater investment in these proven and cost-effective programs.

Thank you for your past and future support.

**STATEMENT ON AMYLOIDOSIS**

**BY**

**ANN D. PEEL**

**PRIVATE CITIZEN, BETHESDA, MARYLAND**

**THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,**

**EDUCATION AND RELATED AGENCIES**

**COMMITTEE ON APPROPRIATIONS**

**U.S. HOUSE OF REPRESENTATIVES**

**APRIL 29, 2015**

Mr. Chairman,

Amyloidosis is a rare, often fatal disease. I ask that you include language in the Committee's report for fiscal year 2016 urging the National Institutes of Health and other health agencies to fund research for amyloidosis and to increase awareness of the disease.

I have endured two stem cell transplants in order to fight the deadly disease amyloidosis. I am one of the lucky amyloidosis patients who has survived the disease and the risky treatment for the disease. I want to use my experience to help save the lives of others.

Amyloidosis can cause heart, kidney, or liver failure and severe neurologic problems. Left untreated, the average survival is only about 15 months from the time of diagnosis. Amyloidosis can literally kill people before they even know that they have the disease.

Although progress has been made in research and treatment for various types of amyloidosis, researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. More research needs to be funded.

The patients with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell transplantation or organ transplantation. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis

Amyloidosis is vastly under-diagnosed. .

### **AMYLOIDOSIS**

Amyloidosis occurs when unfolded or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace. I have been treated for primary (AL) amyloidosis, a blood or bone marrow disorder.

In addition to AL amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. It was not until the early 1980s that the most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is the form of amyloidosis that may be present in a significant number of African-Americans.

Older Americans are susceptible to heart disease due to amyloidosis formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

It was not until the 1980s that research identified the most common amyloid proteins and rationales for treatment were being discussed. The first clinical trial using oral chemotherapy for primary amyloidosis was begun in the late 1980s, and high dose chemotherapy with stem cell transplantation was developed in 1994.

The first liver transplant in the United States for familial amyloidosis was performed in 1992.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal. There is no explanation for how or why amyloidosis develops and there is no known reliable cure.

### **AMYLOIDOSIS TREATMENT**

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell replacement is an effective treatment in selected patients with primary amyloidosis. Abnormal bone marrow cells are killed through high dose chemotherapy and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

The high dose chemotherapy and stem cell rescue and other new drugs have increased the remission rate and long-term survival dramatically.

However, more research needs to be done to provide less risky forms of treatment.

### **RESEARCH, DIAGNOSIS AND TREATMENT**

Researchers are moving forward with limited funding to develop targeted treatments that will specifically attack the amyloid proteins. Additional funding for research and equipment is needed to accomplish this task. Only through more research is there hope of further increasing the survival rate and finding treatments to help more patients.

Timely diagnosis is also of great concern. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

Early diagnosis and treatment is the key to success. More needs to be done in this area to alert health professionals to identify this disease.

### **CURRENT INITIATIVES**

Through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred.

- The National Institutes of Health has substantially increased its interest in amyloidosis. The NIH, particularly the Office of Rare Diseases, participates in meetings and symposia and works closely with organizations doing research and outreach on amyloidosis.
- Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration has led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis. This represents the first readily available drug treatment for this

disease. There is also hope, with increased funding for research, to expand the range of treatment to other categories of amyloidosis.

- There has been increased basic and clinical research at the Boston University Amyloidosis Center: models of disease have been developed; factors that cause protein misfolding are being identified; and new clinical trials are underway. A study of the age-related form of amyloid heart disease will provide natural history data critical for the design of future clinical trials. The National Institute of Aging is supporting this work.
- Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

#### **REQUEST FOR FISCAL YEAR 2016**

Mr. Chairman, I ask that the Committee take the following actions to help address this deadly disease:

- First, include language in your report identifying amyloidosis as an important concern and encouraging more research to find a cure.
- Second, continue to encourage the Centers for Disease Control and the National Institutes of Health to educate the American public and medical profession on the need to diagnose this disease at an early stage.

The United States Congress and the Executive branch working together are essential to finding a cure for and alerting people to this terrible disease. Help me turn what has been my own life-threatening experience into hope for others.

Thank you for your consideration.



COMMUNITY SERVINGS

national food bank coalition

**Testimony Prepared by Community Servings for the United States House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White HIV/AIDS Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation, and halting the devastating effects of the HIV Treatment Cascade.

Community Servings is part of a nationwide coalition, the *Food is Medicine Coalition*, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. We provide over half a million medically tailored, home-delivered meals to critically and chronically ill individuals, their dependent families, and caregivers in twenty cities and towns in Massachusetts annually. Collectively, the *Food is Medicine Coalition* is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids

and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White HIV/AIDS Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. MNT also includes medically tailored home-delivered meals (MTMs) referred by a physician and developed by an RDN.

The range of FNS provided through the Ryan White HIV/AIDS Program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, MTMs and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and MTMs as a clinically effective core medical service in the Ryan White HIV/AIDS Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion services like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV.



When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **(a) Better Health Outcomes**

When clients receive effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>i</sup> Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. In contrast, PLWHA who are food insecure face dire outcomes, such as:

- Lower CD4 counts and lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> and increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy.<sup>vi</sup>

#### **(b) Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS.<sup>vii</sup> If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution.<sup>viii</sup> Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### (c) Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life.<sup>ix</sup> Clients overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### 4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time,<sup>x</sup> thus, FNS is key to prevention.<sup>xi</sup>
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.<sup>xii</sup>
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.<sup>xiii</sup>

### Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet the funding of the Ryan White HIV/AIDS Program at \$2.45 billion for FY16 is critical to ensuring that all people living with HIV receive treatment and remain in care, and limit the spread of the disease and its devastating impact on public health.

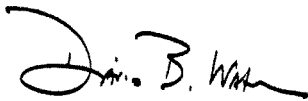
In addition, research shows that investment in MNT and MTMs, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A patient's diet can literally have life and death consequences. When people are severely ill, good

nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White HIV/AIDS Program and the Affordable Care Act.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY16 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our national research partners.

Thank you.



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<sup>i</sup> Aidala A, Yomogida M, Vardy Y and the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services\\_chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services_chain_factsheet3.pdf).

<sup>ii</sup> Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at [http://www.adaevidencelibrary.com/conclusion.cfm?conclusion\\_statement\\_id=250707](http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707) Accessed 29 July 2012.

<sup>iii</sup> Aidala A, Yomogida M, and the HIV Food & Nutrition Study Team (2011).

<sup>iv</sup> Id.

- <sup>v</sup> Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277
- <sup>vi</sup> Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).
- <sup>vii</sup> Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, and Lavery N. Examining Health Care Costs Among MANNA Clients and a Comparison Group, *J Prim Care Community Health*, 4(4):311-7 (June 3, 2013).
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- <sup>x</sup> M. S. Cohen *et al.*, "Prevention of HIV-1 Infection with Early Antiretroviral Therapy," *N. Engl. J. Med.* **365**, 493-505 (2011). HPTN 052
- <sup>xi</sup> Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141<sup>st</sup> Annual Meeting, Boston, MA, November 5, 2013.
- <sup>xii</sup> Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at [https://www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/key\\_resources/housing\\_and\\_supportive\\_services/chain\\_factsheet3.pdf](https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf)
- <sup>xiii</sup> Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. *J Gen Intern Med.* 2009 Jan;24(1):14-20. doi: 10.1007/s11606-008-0824-5. Epub 2008 Oct 25.

04/28/15

To: U.S. House of Representatives Committee on Appropriations  
 Subcommittee on Labor, Health & Human Services, Education and Related Agencies

I am writing on behalf of the Autistic Self Advocacy Network to support continued appropriations to support Home and Community-Based Services (HCBS) and community integration-related activities. ASAN is the leading national organization representing Autistic Americans, and our membership includes people with a wide range of support needs who receive a wide range of Home and Community-Based Services. On behalf of our membership, ASAN vigorously advocates for continued appropriations to support Home and Community-Based Services, including efforts that would lead to downsizing or closure of institutional or segregated facilities such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), congregate residential facilities, sheltered workshops, or segregated day habilitation programs. These activities may be conducted by any component of HHS, including the Administration on Intellectual and Developmental Disabilities (AIDD), the National Council on Disability (NCD), and the Centers for Medicare & Medicaid Services (CMS). Far from depriving individuals of choice, these efforts help to rebalance public spending toward the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Community integration efforts help bring federal funding for disability-related services into alignment with the 1999 *Olmstead* decision, which requires services to be delivered in the most integrated setting possible. Many people with disabilities who need long-term services and supports continue to be forced into nursing facilities and other institutions against their will because adequate community-based services were not available. Segregated and institutional settings are rife with opportunities for abuse, in addition to being significantly more costly than community-based settings.

An essential component of community integration efforts is enforcement of regulations that ensure that federal funds specifically earmarked for integration are not used to fund institutional or segregated placements. In order to make community-based services available, it is often necessary to rebalance funding toward community-based services as opposed to institutional settings. For example, Congress authorized federal reimbursement to states who provide Home and Community-Based Services through their Medicaid programs. HCBS programs were designed specifically to promote fully integrated service delivery settings in the community—in other words, supporting the self-determination of people with disabilities by providing meaningful choices for where they can live, work, and receive services in their own homes and communities. It is vitally important that HCBS funds are not used for any settings, programs, or types of services that are not truly integrated and based in the community. Inclusion of any language prohibiting use of congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice and force them to live and receive services in restricted and segregated settings instead of the community.

People with disabilities have fought for decades to make meaningful choices about community-based options a reality. We believe that all people should have the right to stay in their own

communities, and that it is imperative for the past several decades' move away from institutions to continue. We urge the Appropriations Committee to ensure that HHS is able to continue its vital work on HCBS implementation and community integration. This work will ensure that many more people with disabilities have the opportunity to transition out of unnecessarily restrictive settings and live in fully integrated communities.

Sincerely,

Ari Ne'eman

President, Autistic Self Advocacy Network

Washington, DC

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# NEW LEADERS

## CONGRESSIONAL APPROPRIATIONS TESTIMONY

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Testimony of Jean Desravines, CEO

**Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**  
**Re: FY2016 Labor, HHS, Education and Related Agencies Appropriations Bill**  
**April 29, 2015**

Thank you for the opportunity to provide testimony regarding the FY2016 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. This process represents a tremendous opportunity to create positive, lasting change in our education system and I hope that New Leaders can provide useful insights to help guide your decisions on these important issues.

New Leaders is a national non-profit dedicated to enabling high academic achievement for all children by developing transformational school leaders and advancing the policies and practices that allow great school leaders to succeed. Since our founding in 2000, we have helped to train and equip more than 1,600 school leaders with the knowledge and skills to positively impact the lives of more than 350,000 children, many of whom are students of color and come from low-income backgrounds.

New Leaders is committed to making every school a place where great teachers love to teach and all students love to learn. We can reach this goal by paying more attention to how our schools—not just individual classrooms, but all classrooms within a school—are organized and led. The current appropriations process is an opportunity for Congress to show it is serious about improving student outcomes—by making meaningful investments in the programs that will enable and empower great principals to create schools where teachers can thrive and students can excel.

Our more than 15 years of experience have helped us to identify the following priorities, which are critical for the development of effective principals and other school leaders, as well as the improvement of outcomes for students,

particularly economically disadvantaged and other at-risk students. We hope that you will consider these priorities during your upcoming negotiations.

- The School Leadership Program (SLP), which provides grants to high-poverty school districts to assist in the recruitment, preparation, and retention of effective principals, is the only program currently in the federal budget dedicated to school leadership. SLP gives high-poverty districts the resources to develop dynamic leaders who have a measurable, positive impact on student achievement; leaders like Principal Alison Harris and Assistant Principal Erica Jordan-Thomas at Ranson Middle School in Charlotte, North Carolina. After training and support from New Leaders, Principal Harris and Assistant Principal Jordan-Thomas helped Ranson become the second highest performing Title I school in the district in terms of student growth. It is critical that we continue to provide school districts with the resources to develop effective school leaders and pursue professional development practices that have shown evidence of effectiveness. **We recommend that the FY2016 appropriation continue funding for a dedicated school leadership program. We would support funding the current SLP at \$38.8 million, a substantial increase over the FY2015 level.** We would also be supportive of the President's proposal to replace and build on SLP through the Teacher and Principal Pathways as long as the dedicated funding stream for principal effectiveness includes support for both aspiring principals as well as and current principals and their instructional leadership teams. **We would also support \$138.8 million in funding for the Teacher and Principal Pathways program proposed in the Presidents FY2016 budget request, including \$38.8 million dedicated specifically to principleals.**
- The Investing in Innovation Fund (i3) supports the development, validation, and scaling up of innovative strategies and interventions for addressing persistent education challenges. The Department has established priorities for i3 relating to (1) developing and implementing models for principal preparation that deepen proven leadership skills, and (2) increasing equitable access to effective teachers and principals for student from low-income families and other high-needs students. Thus, i3 can play a key role in identifying and expanding school leadership development programs that truly have a positive effect on student achievement



and school performance, especially in predominantly low-income districts. Take Green Street Academy in Baltimore, Maryland: New Leader Principal Crystal Harden-Lindsey is hyper focused on the success of her teachers in this innovative secondary school. Since assuming the principalship in 2012, Principal Harden-Lindsey has supported the development of five Emerging Leaders, teacher leaders who learn to lead teams of teachers to meet school improvement goals, and two Aspiring Principal Residents, educators on the path to becoming transformational school leaders. This “leadership lab” approach is enabling Principal Harden-Lindsey and her team to turn around one of the lowest-performing schools in the area and has been supported, in part, by New Leaders’ i3-funded leadership programming. **New Leaders recommends funding i3 at a level of \$300 million, the amount requested by the Administration.**

- The Teacher Incentive Fund (TIF) provides for the development and implementation of sustainable, performance-based compensation systems for teachers, principals, and other personnel in high need schools in order to increase educator effectiveness and student achievement. This program has been instrumental in helping schools and districts move from a pay system based primarily on seniority to one that focuses on student outcomes. TIF helps send the message that the ultimate goal is to enable meaningful learning for all kids—regardless of their background, zip code, native language, or developmental needs. Take Memphis City Schools in Memphis, Tennessee: recognizing the need for strategic compensation to recruit, support, and retain great teaching talent, the district sought out data. Based on local survey information from New Leaders’ EPIC Knowledge Management system (created in part with TIF funding)—including that 81 percent of school leaders and 77 percent of teachers said that higher salaries are “very important” or “absolutely essential” in retaining effective teachers and 96 percent of teachers said that supportive leadership was critical to their decision to continue teaching—the district developed a compensation structure with higher salaries tied to performance rather than years of experience or education. The district also recognized the critical role of the principal in creating and maintaining a supportive context where teachers want to work. **New Leaders recommends at least \$350 million in funding for TIF in FY2016—the amount requested by the Administration—and a continued focus on broader human capital**

**systems in schools.** These human capital systems include a deeper focus on school leadership, in part recognized by re-naming it the Teacher and Leader Incentive Fund.

- Supporting Effective Educator Development (SEED) makes grants to national nonprofit organizations for projects that recruit, select, and prepare, or provide professional development activities for, teachers or principals. The importance of recruiting, training, and retaining effective school leaders cannot be overstated; principals can account for as much as 25 percent of a school's effect on a certain student's achievement,<sup>1</sup> and 97 percent of teachers say that the principal is responsible for determining if a school can attract and retain great teachers.<sup>2</sup> It is imperative that we make the necessary investments in evidence-based programs that help develop and retain these leaders. **New Leaders recommends that SEED be funded with \$117.5 million in set-aside funds in FY2016, as recommended in the Administration's budget request.** We also recommend that these funds continue to be used for non-profits that support either teachers or leaders or both.
- School Improvement Grant (SIG) provides funding to state education agencies (SEAs), which the SEAs use to make competitive subgrants to districts that demonstrate the greatest need and the strongest commitment to use the funds to support students in their lowest-performing schools. The SIG program is designed specifically to support the lowest performing schools—those that are most in need of strong leadership. In fact, research has shown that improvement simply does not occur without strong school leadership.<sup>3</sup> Take Fenger High School in Chicago, Illinois: in 2011, Fenger received a 3-year school improvement grant totaling more than \$5.5 million. New Leader Principal Elizabeth Dozier used the turnaround model framework and federal funds to completely re-staff the school and bring in supplemental academic, social, and emotional support services for her students. The results of Principal Dozier's school improvement

<sup>1</sup> Leithwood, K., Louis, K. S., Anderson, S., & Wahlstrom, K. (2004). *How Leadership Influences Student Learning*. New York, NY: Wallace Foundation.

<sup>2</sup> Scholastic Inc. (2012). *Primary Sources: America's Teachers on the Teaching Profession*. New York, NY: Scholastic and the Bill and Melinda Gates Foundation.

<sup>3</sup> Bryk, A. S., Sebring, P. B., Allensworth, E., Luppescu, S., & Easton, J. Q. (2010). *Organizing schools for improvement: Lessons from Chicago*. Chicago, IL: University of Chicago Press. Aladjem, D. K., Birman, B. F., Orland, M., Har-Robins, J., Heredia, A., Parrish, T. B., & Ruffini, S. J. (2010). *Achieving dramatic school improvement: An exploratory study*. Washington, DC: U.S. Department of Education. Louis, K. S., Leithwood, K., Wahlstrom, K. L., & Anderson, S. E. (2010). *Investigating the links to improved student learning: Final report of research findings Learning from Leadership Project*. Minneapolis, MN: University of Minnesota.

strategies were profound: the percentage of students meeting or exceeding state standards more than doubled in just three years. **New Leaders recommends \$555.8 million in FY2016 funding for SIG, the same as recommended in the Administration's budget request; in particular, New Leaders supports the Turnaround School Leaders Program that funds efforts to select, prepare, support, and retain school leaders in SIG schools.**

Thank you for the opportunity to provide the views of New Leaders on the FY2016 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact our Chief Policy Office, Jackie Gran, at [jgran@newleaders.org](mailto:jgran@newleaders.org).



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**TRUSTEE**

**HELEN KELLER INTERNATIONAL**

**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,**

**EDUCATION AND RELATED AGENCIES**

**COMMITTEE ON APPROPRIATIONS**

**U.S. HOUSE OF REPRESENTATIVES**

**APRIL 28, 2015**

Mr. Chairman, thank you for this opportunity to provide testimony to the Subcommittee on behalf of Helen Keller International's ChildSight® program. My name is Gregory Feller and I serve as a member of the Board of Helen Keller International (HKI). I am requesting that this Subcommittee recommend that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families in fiscal year 2016.

It is HKI's hope that with the continued support of the Department of Education and private donors, we can deliver free vision screenings and eyeglasses to thousands of economically disadvantaged children who have extremely limited access to immediate and affordable vision care.

**CHILDSIGHT®**

Established in 1994, ChildSight® tackles the common problem of refractive error among children and adolescent students in underserved communities in the United States. More commonly known as nearsightedness, farsightedness, and astigmatism, refractive error affects one in four children and adolescents nationwide. The mission of ChildSight® is to improve the vision and academic potential of economically disadvantaged children. Research has established a clear link between vision and learning. Most learning platforms – books, computer screens, blackboards and classroom presentations – require clear vision in order for a child to interact, assimilate information and respond. Yet in thousands of classrooms, millions of children are unable to make the most of their education, simply because they cannot see well. This is especially tragic since most cases of poor vision are due to refractive error and are easily corrected.

If not detected and treated promptly, refractive error and other eye conditions can lead to long term visual deficiencies and developmental problems. Students must have clear, healthy eyesight in order to fully focus on schoolwork and classroom lessons or the opportunity to gain a valuable education is severely diminished. Adults whose visual impairment denied them the chance to gain core academic skills are at a disadvantage in seeking employment and achieving economic independence.

In most cases, the solution is simple: the provision of correctly prescribed eyeglasses. ChildSight® helps students directly by going into the schools to conduct vision screenings, identifying children with refractive error and providing prescription eyeglasses to address this need, all free of charge. In so doing, ChildSight® “brings education into focus™” for children who would otherwise be left with untreated vision problems – and lost opportunities.

Millions of students do not get the care they need due to limited access to vision screening and the prohibitive cost of a pair of prescription eyeglasses. ChildSight® targets these communities and serves at-risk children by providing free on-site screening, free eyeglasses and follow-up care so that students can focus in the classroom in order to achieve their potential for future academic and vocational success.

ChildSight® is distinguished by its high clinical standards and its efforts to educate children and their families about the importance of corrected vision and the availability of related healthcare resources in their community. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist who prescribes the necessary lenses for each child.

ChildSight® goes one step further. Students identified with potentially severe eye conditions beyond basic refractive error are referred to our partnering ophthalmologists for a full eye exam and follow-up treatment as needed. This final step ensures that children who need further assessment and care will be able to receive it.

### **POSITIVE RESULTS**

Since its inception, ChildSight® has screened over 1.7 million children and delivered over 243,000 pairs of free eyeglasses to children in need, with support from this Subcommittee, the Department of Education and private donations. We have seen the positive results of the ChildSight® program.

Teachers we have surveyed throughout the country report that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited significant improvement in the completion of schoolwork and homework; increased class participation and a reduction in disruptive behavior; and improvement in grades, self-confidence and self-perception as reported by the teachers.

## **PUBLIC/PRIVATE UNDERTAKING**

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of our partner physicians, educators, community activists and business people in each of our local sites. With their support and the contributions of foundations and corporations, we continue to seek the institutionalization and long term sustainability of our programs.

The endorsement and support of the Department of Education have played an integral role in our ability to leverage committed support from the private sector. ChildSight® has received significant long term funding from foundations including The Community Foundation for Greater New Haven, Lavelle Fund for the Blind, Mt. Sinai Health Care Foundation, The New York Community Trust, Children's Aid Society, The Rose Hills Foundation, Victoria Foundation, The Healthcare Foundation of New Jersey, and Reader's Digest Partners for Sight Foundation.

Local health care professionals, such as optometrists, pediatric ophthalmologists and opticians, at our program sites are members of the ChildSight® team who help us meet the vision care needs of the students we serve. ChildSight® contracts with ophthalmic clinics and optical shops selected according to their strong professional credentials. The services of these community professionals are either donated or provided at a reduced, reasonable rates.

## **CONCLUSION**

ChildSight® provides an invaluable – and often life changing – service to local youth in a pragmatic and cost-effective manner. I ask this Subcommittee to recommend in its fiscal year 2015 Committee report that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families. These Department of

Education funds will support ongoing programs and will provide vision screening and prescription eyeglasses for such children.

As our founding board member Helen Keller said: *We are never really happy until we try to brighten the lives of others.*



**Person Submitting Testimony:** Janet Price-Ferrell 3 Ballantree Drive Asheville, NC 28803, parent of 19 year old with IDD, Executive Director of F I R S T , a parent center funded by OSEP and other funding sources.

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies, including Administration on Intellectual and Developmental Disabilities (AIDD), National Council on Disability (NCD), and Centers for Medicare & Medicaid Services (CMS)

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

I am not seeking any funding for any agency, but write to support community inclusion of persons with disabilities, all disabilities. I am seeing sad support of separate and institution settings for persons with IDD by organizations that gain by the separate communities that have been created.

My son who is eligible for ICF IDD Level of care has been including in public schools, in general education classrooms since he was 4 years old. He has learned the social norms and can participate socially in public. He has friends in our community that have known him at school. They have stood next to him in chorus, ate lunch with him, worked on science projects and NO

Austin cannot read, barely write and maybe knows his coins. BUT Austin is part of the community.

When he transitioned to middle school, where school merged, a small group of students who did not know him started teasing him. The students that had been in school with Austin came to his aid and have never allowed him to be bullied. This is what inclusion can create. As long as there is a place to send folks, they will be send there whether or not it is the right place.

When a person is put into a place where they are supervised by a few people who are regulated around that care and paid minimum wage, you are not safe long. All the horror stories we have heard were started with good intentions or so it seems. But over time human nature, or greed take over and those people become just care takers and those good intentions are no longer good. This is discrimination at the lowest level. Persons with IDD should not be housed in settings that are separate from others in the community like criminals.

The movement to stop the work of inclusion is the greed of the institutions that had a history of high daily rates and low levels of care. Examples:

- Van therapy where all the residents are put in vans and given tours around town, because they like to ride around
- All residents are put on Miralax to maintain bowel function which has been hindered because of over medications and bad diet.
- Physical restraints are used to keep residents “safe” like leaving them in their wheel chairs locked looking out the window or left in beds.
- Living with a roommate that they do not choose and probably do not like.

This is not how I want to live or how I want my son to live. This is not best practices and creating laws or regulations that do not follow best practices should not be allowed. The costs of

community care in North Carolina is 15% at least by law. Residents in ICF IDD cost from \$100,000 to \$175,000 per year and community supports on the average is \$70,000. **PLEASE DO NOT SUPPORT** language to *prohibit* HHS-funded deinstitutionalization activities. Federal agencies are not defining “choice” so narrowly but supporting best practices and community supports over institutions for persons who have not committed a crime.



**Testimony Prepared by Marc Marger, Chair of the Orange County HIV/AIDS Advocacy Team for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Orange County HIV/AIDS Advocacy Team is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In Orange County, we provide 5,100 food pantry orders (equivalent to 244,800 meals) and 69,550 cans of nutritional supplements such as Ensure annually to low income, disabled HIV+ individuals. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase

absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a

control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

## Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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**Person Submitting Testimony:** Staci K. Converse, Managing Attorney, Disability Rights Maine, 24 Stone Street, Suite 204, Augusta, ME 04330

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov) (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of Disability Rights Maine, the Protection and Advocacy (P&A) agency for Maine on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from

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MAINE'S PROTECTION AND ADVOCACY AGENCY FOR PEOPLE WITH DISABILITIES

abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, Disability Rights Maine's PADD program served 745 individual clients, held 100 trainings with 1,332 people trained, and provided informational and referral services to an additional 405 people. In addition to these activities, 4,500 people were impacted by the activities undertaken by Disability Rights Maine on behalf of individuals with developmental disabilities. These activities benefited individuals in every state and territory in the United States.

As an example of the work done by Disability Rights Maine concerning community integration and accessing services for people with intellectual and developmental disabilities, below are some examples of our work on these topics from 2014.

#### **Nursing home residents celebrate long awaited move to the community**

As a result of the settlement of a class action filed by DRM, eleven individuals with developmental disabilities, including some who had lived in a facility for more than a decade, moved into the community. Under a settlement agreement the State of Maine agreed to create a new home and community based waiver program to allow those who formerly had no choice other than to live in nursing facilities to live in the community and still receive services they need. Class members are thriving in the community, including two named plaintiffs who have enrolled in college.

**Advocacy helps young girl leave institution, obtain proper community placement**

The Disability Rights Maine was contacted on behalf of a 15 year-old Maine girl with intellectual disabilities and mental illness who was a state ward. The girl was ready for discharge from an acute psychiatric unit, but her application for residential treatment was denied. She had been repeatedly unsuccessful in foster homes and no foster placement was available. The DRM advocate participated in team meetings and intervened with Department officials and provider agencies about the support the client needs in the community. As a result of advocacy recommendations, Maine's Office of Child and Family Services contracted with a service provider to arrange a unique foster family situation allowing the young girl to return to the community and get the services and supports she needs.

**DRM files amicus brief opposing effort to circumvent behavior review process**

A 26 year-old female with an intellectual disability requested advocacy assistance because of locks on her refrigerator and kitchen cabinets, locking away of sharp instruments, and removal / confiscation of her personal items on the grounds that she was allegedly hoarding. She requested DRM assistance at all future meetings, state-required committee reviews of her severely intrusive behavior plan, and other situations where she needed advocacy assistance with respect to her parent / guardian and her service provider to give effect to her requests and rights. The DRM attorney did all of the above over several months, culminating in the filing an Amicus Curiae Brief when the guardian attempted to circumvent the committee review process by filing a motion in probate court to amend the Ward's Guardianship plan. The motion was

denied in full. The Motion for DRM to intervene was also denied as to intervention, as intervention was not needed because the Guardianship Plan was rejected. The Probate Court accepted and reviewed the DRM's Amicus Curiae Brief.

#### **DRM aids client in securing services and averting guardianship**

DRM was contacted by a young woman with an intellectual disability as she was concerned that an incident had occurred in her home and as a result she might be subject to guardianship and/or forced to live in a supervised setting. The client fled from an abusive situation and was receiving emergency housing at the time. Her case manager was attempting to convince the Department of Health and Human Services that she lacked capacity to make her own decisions. DRM worked with the young woman to understand the context of the situation she faced, and to provide her with information about her rights, alternatives to guardianship, the grievance process, and potential services for which she is eligible. DRM participated in meetings to develop her Person Centered Plan and secure appropriate services for her and helped develop an intervention plan that addressed the concerns that threatened her autonomy. Due to DRM intervention the client continues to remain her own guardian and is in the process of moving into permanent housing of her choosing. Advocacy helps young girl leave institution, obtain proper community placement.

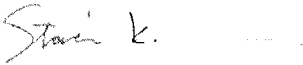
#### **Representation results in restoration of some decision making authority**

A man with a developmental disability who had been under full private guardianship for decades contacted the DRM because his private guardian wanted to

move him to another residence against his will. At a day-long hearing, with DRM's representation, the client's persuasive testimony won out over two medical experts who initially recommended guardianship. As a result, the Court entered an order removing his private guardians, appointing the State of Maine as the client's limited guardian for medical decisions only, and returned to him the authority to decide where he chose to live and receive services.

Thank you for this opportunity to submit this testimony.

Sincerely,

A handwritten signature in dark ink, appearing to read "Staci K. Converse". The signature is written in a cursive, flowing style.

Staci K. Converse

Managing Attorney



**Testimony Prepared by Stephen Hourahan, Executive Director of AIDS Project Rhode Island for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

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**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase

absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

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## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

## **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a

control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

## **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

## Conclusion

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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April 29, 2015

Debra Fults  
Executive Director  
disAbility Resource Center of the Rappahannock Area, Inc.

Submitted to: U.S. House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

Regarding: Flexibility for HHS Agencies to fund community-based services

I respectfully submit this testimony to support continued funding of U.S. Department of Health and Human Services (HHS) Agencies, including the Administration on Intellectual and Developmental Disabilities, the National Council on Disability, and the Centers for Medicare & Medicaid Services used for community-based services for people with disabilities, including those funds used to provide community-based supports for people with I/DD who are exiting Intermediate Care Facilities and other institutional settings.

The disAbility Resource Center of the Rappahannock Area, Inc. (dRC) is a Center for Independent Living (CIL) serving the Fredericksburg, VA Region. CILs are cross-disability, non-residential, community-based, nonprofit organizations that are staffed and run largely by people with disabilities for people with disabilities. The dRC supports people with disabilities in living as independently as possible in our community. This cannot occur when people live in institutional settings.

Any restrictions placed on HHS Agencies' use of appropriations for community-based services, including those that assist people with I/DD in transitioning out of Medicaid-funded institutions, would negatively impact their opportunities to live independent lives as fully-integrated members of our community. Robust community-based supports for individuals with I/DD are fundamental for independent living and reflect the spirit of the Supreme Court's *Olmstead* decision and the integration mandate of the Americans with Disabilities Act. They are also essential for realizing Congress's commendable vision of community integration

conveyed through the recent passage of the Workforce Innovation and Opportunity Act. Restricting agencies' flexibility to use funding for community-based I/DD services would hinder progress toward full-integration and, as community-based services are significantly less costly than institutional living, reduce cost-savings to Medicaid, Medicare, and state taxpayers.

In the Fredericksburg, VA Region, the dRC currently provides case management support to over 70 people with Developmental Disabilities (DD) receiving community-based services through one of Medicaid's Home and Community-Based Waivers. Part of this support involves coordinating often numerous providers and resources. For many, the services provided through this waiver are all that stands between living at home or living in an institution. These services are also integral for the hundreds of individuals transitioning out of Virginia's training centers as a result of *Olmstead*. From our perspective, the networks of providers and resources are largely inadequate to meet the growing need. HHS Agencies should be provided more flexibility, not less, to use appropriations to meet the expanding demand. While opponents of deinstitutionalization may argue that funding for community-based services and closing Medicaid-supported institutions somehow limits choice, our experience suggest otherwise. In 4 years of providing case management for people with DD, no one has requested to move from living in the community with supports to an institutional setting. If choice has been limited, it has in fact been in terms of the number of community-based providers and resources available. Expanding choice for people with DD should involve more flexibility for agencies use appropriations to fund community-based services, not less. I strongly support continued funding for community-based services and oppose any funding restrictions on the closure of institutions. HHS Agencies should retain the flexibility to fund services that support people with DD in living as independently as possible.

Thank you for the opportunity to provide this written testimony.

Respectfully submitted,



Debra Fults  
Executive Director



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April 29, 2015

Debra Fults  
Executive Director  
disAbility Resource Center of the Rappahannock Area, Inc.

Submitted to: U.S. House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

Regarding: Increased funding for Independent Living

I respectfully submit this written testimony to support the National Council on Independent Living's (NCIL) request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS budget for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for a total of \$306 million for the Independent Living line item in FY 2016.

The disAbility Resource Center (dRC) is one of 16 CILs in Virginia. CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 356 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and the newly added transition services. From 2012-2014, CILs provided the four core service to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. The dRC provides services to approximately 3,000 people each year in the Fredericksburg, VA Region.

Transition services were added as a fifth core service with the passage of the Workforce Innovation and

Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include transitioning individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, helping individuals with significant disabilities at risk of entering institutions to remain in the community, and assisting youth with significant disabilities transition to adult life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over their own lives. We know that this cannot occur when people reside in institutional settings. While opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm, we know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions across the country from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

The dRC, like many other CILs, maximizes every dollar and accomplishes its broad ranging mission with relatively little funding. However, since transition services were added as a core service, the need for funding is more critical than ever. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2015, the Independent Living Program is receiving nearly \$3 million less in funding than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work



tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Thank you for the opportunity to provide this written testimony.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Debra Fults", with a stylized flourish at the end.

Debra Fults  
Executive Director

**Testimony of Janel Wright, JD, Chair, Board of Directors, American Diabetes Association  
U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education  
Contact: Lisa Cox, Associate Director, American Diabetes Association, lcox@diabetes.org**

For Fiscal Year (FY) 2016, the American Diabetes Association (Association) urges the Subcommittee to deepen its investment in research and prevention to find a cure, and improve the lives of those living with, and at risk for, diabetes. We ask the Subcommittee to provide \$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), \$140.129 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and \$20 million for the National Diabetes Prevention Program (National DPP) at CDC.

The nearly 105 million American adults and children living with diabetes and prediabetes come from all walks of life. I have been living with type 1 diabetes since I was 13 years old. When I was diagnosed almost 40 years ago, I was told I shouldn't expect to live to age 50. Thanks to the work of NIDDK and DDT, advancements in diabetes treatment have allowed me to lead a productive life. However, not a moment goes by when I'm not thinking about whether my blood sugar is within the range to prevent diabetes' devastating complications. The constant concern leaves me weary and longing, hoping for a cure everyday. I was told the cure was just around the corner when I was diagnosed; it has been a long, difficult block. Additional federal resources at NIH and CDC are needed to make it around the corner to a world free of diabetes and its devastating complications. I am honored to share the stories of several Association volunteers who are living with or affected by diabetes.

Like other American Indians, John Beaver from Tulsa, Oklahoma has witnessed the spread of diabetes in his family and community. John's father and many of his aunts and uncles have type 2 diabetes and he doesn't know of an American Indian family untouched by the disease. Sadly, many of his father's siblings (including all of his brothers) are no longer here because of diabetes. John's father remains active and strong and serves their tribe as an elected member of the Muscogee (Creek) Nation National Council. He exercises, watches his diet and utilizes an insulin pump, and while he never says it, John knows some days are difficult for his father.

John is thankful that his father, unlike his uncles, has not experienced many of the difficulties associated with diabetes and that advances as a result of federal funding have improved his prognosis. John says that we need a cure and funding for NIDDK, DDT, and the National DPP.

In April of 2014, Stovy Bowlin from Cedar Creek, Texas faced the fight of his life. He was diagnosed with type 2 diabetes, and underwent emergency surgery as a result of the disease. After recovering, Stovy became a certified lifestyle coach of the National DPP, working to bring this proven program based on successful research at NIDDK and DDT to Cedar Creek. He urges increased funding to continue the National DPP's critical mission.

Floridian Anastasia Albanese-O'Neill wants a different life for Cassidy, her 14 year-old daughter with type 1 diabetes, and Jackson, her 10 year-old son who is at risk for diabetes. That's why Cassidy participates in the NIDDK's Search for Diabetes in Youth (SEARCH) Study, which assesses the impact of type 1 and type 2 diabetes in youth to improve prevention efforts. Jackson participates in The Environmental Determinants of Diabetes in the Young (TEDDY) study, to help unravel environmental factors contributing to type 1 diabetes. Anastasia urges Congress to invest in NIDDK's work.

The disabling, deadly and growing diabetes epidemic is an American story touching all of our lives. According to the CDC, one in three adults in our country – one in two among minority populations – will have diabetes in 2050 if present trends continue. The sobering cost of this horrific disease is lived everyday by those who endure blindness, suffer heart attacks and strokes, wrestle with kidney failure and lose limbs, along with other deadly complications. My life and those of many other people living with, and at risk for, diabetes are better because of NIH research and CDC prevention activities. Progress has been great, but much more must be done. Every year, 1.7 million Americans aged 20 years or older are diagnosed with diabetes. That means 4,660 Americans learn they have diabetes each day – one American every 19 seconds. In addition to the horrendous physical toll, diabetes is economically devastating to our country. A 2014 report found the total annual cost of diagnosed and undiagnosed diabetes, prediabetes, and gestational diabetes in our country has

skyrocketed by an astonishing 48% over 5 years – to \$322 billion. People with diagnosed diabetes have health care costs 2.3 times higher than those without diabetes. One in three Medicare dollars is spent caring for people with diabetes. Despite the escalating cost of diabetes to our nation, the federal investment for diabetes research and programs at the NIH and CDC has not equaled the shocking pace of the diabetes epidemic. This story does not have to be a tragedy. America has the power to stop the diabetes epidemic and make the final chapter a success story for the ages. We believe the state of our nation's diabetes epidemic justifies increased federal funding in FY 2016 for diabetes research and prevention programs.

### **Background**

Diabetes is a chronic disease impairing the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations, and a leading cause of heart disease and stroke. Additionally, an estimated 18 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk for complications and type 2 diabetes. Those with prediabetes have higher than normal blood glucose levels and an increased risk for type 2 diabetes, but can take action to lower their risk for type 2 diabetes.

### **The National Institute of Diabetes and Digestive and Kidney Diseases at NIH**

We request funding for NIDDK of \$2.066 billion in FY 2016 to support innovative research. Thanks to groundbreaking research supported by NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. For example, the continuous glucose monitor and insulin pump I use allow me to better manage blood glucose levels. Because of these advances, my hemoglobin A1C, which provides a snapshot of an individual's blood glucose, went from 12.9%

to 5.9%, greatly increasing my chances of fending off diabetes's complications. This is proof of the importance of NIDDK.

While important strides have been made at NIDDK, our request reflects our concern that, as the diabetes epidemic has grown, funding for the Institute and the research it supports has lost considerable ground. For example, NIDDK was forced to slow the initiation of a comparative effectiveness trial testing different type 2 diabetes medications, delaying critical information about the most beneficial treatments. With \$2.066 billion, NIDDK will not only be able to see the complete restoration of sequestration cuts, but also fund current and additional grants to support exciting studies. This includes work to develop new therapeutic targets for type 2 diabetes and opportunities to study brown fat tissue, which burns calories to generate heat and is a promising target for the development of treatment strategies to combat obesity and type 2 diabetes. Increased funding will also help identify mechanisms underlying the reversal of type 2 diabetes after bariatric surgery.

#### **The Division of Diabetes Translation at CDC**

The federal government's role in coordinating efforts to prevent diabetes and its serious complications is essential. In FY 2015, Congress recognized this by providing \$140.129 million for DDT and its evidenced-based, outcomes-focused diabetes programs. We urge DDT programs be funded at the same amount in FY 2016 to enable DDT to continue its work to eliminate the preventable burden of diabetes. Maintaining resources for diabetes prevention, surveillance, and research programs in FY 2016 will strengthen DDT's work. This will occur through the State Public Health Approaches to Chronic Disease Prevention program (SPHA grant program) and the State and Local Public Health Actions to Prevent Obesity, Diabetes and Heart Disease (1422 grant program). The SPHA program includes programming for diabetes, obesity, heart disease and stroke, and school health. All 50 states receive basic funding to support crosscutting approaches to prevent and control these diseases, and enhanced funding to expand the reach of evidence-based diabetes intervention. The 1422 grant program builds on the SPHA program and focuses on improving community and health system prevention approaches in populations with highest risk for prediabetes and high blood

pressure. These programs support evidence-based community programs to identify, refer, and provide those at high risk for diabetes with cost-effective interventions.

### **The National Diabetes Prevention Program at CDC**

I am alarmed 86 million Americans have prediabetes and are on the cusp of type 2 diabetes. The National DPP is a public-private partnership of community organizations, private insurers, employers, health care organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention. This proven program is a national network of local sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. We urge Congress to provide \$20 million for the National DPP in FY 2016 to continue its nationwide expansion. The National DPP began with a successful NIDDK clinical study showing weight loss of 5 to 7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes per week, reduced risk of developing type 2 diabetes by 58 percent in people with prediabetes and by 71 percent for those over 60 years old. Additional translational research was then done, proving the program also works in the less-costly community setting – at a cost of about \$300-\$400 per participant. Currently, over 1,095 sites are operating the program. Many of these sites have applied for CDC quality standard recognition, which can lead to third-party reimbursement of the program, ensuring long-term sustainability. Stopping the diabetes epidemic is not possible without additional investment in the National DPP. Additional funding in FY 2016 will allow CDC to further expand the program and support provider education and referral networks.

### **Conclusion**

We can and must change our country's story with regard to diabetes. We urge the Subcommittee's FY 2016 appropriations decisions to reflect the necessity of taking action in light of the explosive growth of this horrendous disease. The Association looks forward to working with you to stop diabetes.

**Gary Goosman, President of the National Senior Corps Association**  
**Subcommittee on Labor, Health and Human Services, Education and Related Agencies**  
**National Senior Service Corps FY 2016 (Corporation for National and Community Service)**

Mr. Chairman, Members of the Committee, my name is Gary Goosman and I am Director of the Senior Programs Division at the Corporation for Ohio Appalachian Development. I submit this testimony for your consideration today as President of the National Senior Corps Association, representing the interests and ideals of more than 350,000 senior volunteers throughout the country.

SENIOR CORPS is a federally authorized and funded network of national service programs that provides older Americans with the opportunity to apply their life experiences to volunteer service. Senior Corps is comprised of the Foster Grandparent Program, RSVP, and the Senior Companion Program, through which Americans age 55 and older provide essential services to cost-effectively address critical community needs. I am speaking today about the concern of the NSCA and thousands of elderly Americans that provide services in hundreds of communities. Last year, the President's budget threatened to eliminate service opportunities for approximately 200,000 seniors—nearly two-thirds of those serving in the Retired Senior Volunteer Program (RSVP). This year additional damage will plague these programs if the previous sequestration and other cuts are not mitigated.

As expressed by Congressman DeFazio of Oregon, *"Senior Corps and its associated programs have always received strong bipartisan support because they are a cost effective way to meet local community needs and support the health of American seniors. President Nixon signed the Senior Companion Program into law. President Reagan and First Lady Nancy Reagan were consistent champions of the Foster Grandparents Program. President Clinton logically organized Senior Companion, Foster Grandparent, and RSVP under Senior Corps. President George W. Bush continued support of all three programs. This year should be no different."*

*Unfortunately, the President's FY 2016 budget proposal does not restore cuts the Senior Corps programs absorbed as a result of the sequester, and leaves intact the 20 percent funding cut applied to RSVP in FY 2011."*

The NSCA is in full agreement with Congressman DeFazio and with Ann Maura, CEO of Voices for National Service when she recently said, "At a time when record numbers of Americans are stepping forward to serve and increasing numbers of communities are looking for innovative ways to address local challenges, our country should invest in national service programs."

NSCA respectfully requests the reversal of the 20% cut to the RSVP program. RSVP programs provide critical support to thousands of small, non-profit organizations that are the primary safety net for low income individuals and families in rural and inner city communities. **RSVP** engages senior volunteers that allow these organizations to continue their existence and ensures that our safety net assists those in need. NSCA respectfully requests \$111,241,000 for the **Foster Grandparent Program** and \$47,007,000 for the **Senior Companion Program (restoring funding to levels prior to sequestration)**. This combined expenditure of \$221,248,000 will allow for continued support to existing Senior Corps programs and sponsors. *We also request that, as in the past, the Subcommittee refrain from authorizing through the appropriations process – whether to create a new competitive arrangement for the award of program grants or any other matter more properly considered by the programs' authorizing committee of jurisdiction.*

These grant funds allow existing Senior Corps programs and the nearly 337,000 volunteers to continue providing critical services, including:

**Foster Grandparent Program** provides one-on-one attention to children and youth most at risk in schools, shelters, correctional facilities, early childhood centers and after-school programs. Through a caring, nurturing, mentoring role, Foster Grandparents provide assistance and encouragement to help improve reading skills, school attendance, behavior and the well-being of children in their care. NSCA recommends a return to budget levels from 2013 that would support 27,900 Foster Grandparents contributing 24 million hours (valued at \$531,360,000 based on Independent Sector's data) to help over 232,300 children and youth. Foster Grandparents currently serve through more than 320 federally funded programs nationwide and partner with



over 10,000 community organizations. Returning to 2013 funding levels means over 232,000 children could be provided tutoring, mentoring and one-on-one attention. This also would provide support for nearly 7,000 children of incarcerated parents and 2,250 children of military families. Foster Grandparents are 55 years of age and older with limited incomes (200% of poverty), and serve weekly schedules ranging from 15-40 hours. They are provided with a modest hourly stipends, mileage and meal reimbursements, so that they may volunteer at little or no personal cost to themselves.

**RSVP** connects volunteers 55 and older with service opportunities that impact positive change, improve quality of life and meet critical needs in their communities. Volunteers help build capacity and improve sustainability in agencies and organizations where they serve. **RSVP** engages seniors in a wide array of community services including health, nutrition, human services, education, community and economic development, and public safety to nonprofit and community based organizations. In 2012 there were 296,000 RSVP volunteers, a decrease of over 100,000 volunteers from the 2010 level of engagement. By restoring funding to 2010 levels, thousands of additional RSVP volunteers could be added to improve upon the 62 million hours of service that was recently delivered (valued at \$1,372,680,000 based on Independent Sector's data). This effort would be delivered through more than 685 sponsoring programs nationwide, and work with more than 65,000 community organizations. Volunteers would mentor more than 80,000 children including 16,000 children of prisoners and provided independent living services for 696,000 frail elderly and people with disabilities. RSVP offers flexible volunteer opportunities with commitments from a few hours a week to 40 hours a week. Volunteers do not receive monetary incentives or stipends.

**Senior Companion Program** provides assistance and friendship to frail individuals who are homebound and, generally, living alone. By taking care of simple chores, providing transportation to medical appointments, and offering contact with the outside world, Senior Companions often provide the essential services that enable frail citizens to remain in their homes. The program meets the growing need for cost effective long-term care for the aging by helping with activities of daily living, friendly visits and providing respite for primary caregivers. By restoring funding to 2013 levels, 13,600 Senior Companions could provide 12.2

million hours of service (valued at \$270,108,000 based on Independent Sector's data) through 194 federally funded programs nationwide to help 60,940 frail clients, preventing premature and costly institutionalization. Senior Companions are 55 years of age and older with limited incomes (200% of poverty), and serve weekly schedules ranging from 15-40 hours. They are provided with hourly stipends, mileage and meal reimbursements, so that they may volunteer at little or no personal cost to themselves.

Some prime examples of Senior Corps service are:

- 1) Gene Assink, a Washington RSVP volunteer, has logged 34,694 miles since 1999 driving clients to medical appointments and grocery stores, saving clients and agencies over \$14,000 in mileage costs. RSVP volunteer, Ted Stegemen, draws intricate plans and directs a team of volunteers to make repairs on older homes of low-income neighbors.
- 2) An angry, temperamental 4<sup>th</sup> grade boy ended daily trips to the office after being matched with the encouragement and persistence of 91 year-old Missouri Foster Grandparent, Marie Yeakey, and has now graduated from high school.
- 3) While doing routine housework, a Missouri woman's fall resulted in permanent paralysis of her arms and hands. Three Senior Companions provide caregiver respite for her daughter, the mother of three young children ages 7, 5 and 18 months and son-in-law, a long haul truck driver.
- 4) RSVP of Enid and North Central Oklahoma, Inc. partnered with the Regional Foodbank of Oklahoma and will distribute commodity boxes to people 60 years and older who are food insecure and living in desolate conditions. Volunteers will distribute more than 100 boxes of food every month to their doors.
- 5) RSVP of Enid and North Central Oklahoma, Inc.'s volunteer of the year, Johnny Johnson, has personally provided more than 2,100 miles of volunteer service to help support our isolated seniors in taking them to doctor's appointments, picking up prescriptions, or attending to other daily necessary errands of life.

It has been stated that baby boomer and senior volunteers represent our Nation's single and fastest growing resource. During this unprecedented economic crisis facing our Nation, the number of baby boomer and senior volunteers should be greatly expanded and mobilized as solutions to the problems facing our local communities. We need to provide the opportunity for thousands more older adults to serve in their communities and enhance the lives of those most in need, including children with special needs, the frail and isolated elderly striving to maintain independence, and expanding the services of local non-profit agencies.

CATHERINE DUFF  
FOUNDER, PRESIDENT  
THE FECAL TRANSPLANT FOUNDATION

Ladies and Gentlemen, thank you for the opportunity to address you today regarding one of the most urgent health problems the world is facing, antibiotic resistance. My name is Catherine Duff. I'm just a grandmother, living in Indiana. But my life, and the lives of so many, have been changed, or, all too frequently, ended, because of antibiotic resistance. I am the Founder and President of the Fecal Transplant Foundation, and I am requesting funding of one (1) million dollars to raise awareness and provide education about fecal transplant, through the National Education and Awareness Outreach Program (NEAOP) of The Fecal Transplant Foundation. Fecal Microbiota Transplantation, or FMT, is now often the treatment of last resort for the deadly, antibiotic resistant superbug, *Clostridium difficile*, or *C. diff*.

I first developed *C. diff*. in 2005 after surgery. I was given a strong, broad-spectrum antibiotic. However, rather than curing me, the antibiotic destroyed the healthy bacteria in my colon, allowing for the overgrowth of the deadly *C. diff*. bacteria.

As a result, I was given stronger antibiotics, at higher doses, which did eventually cure the *C. diff*. at first, but which began a common but vicious cycle of infection and subsequent antibiotic use.

Over the next eight (8) years, I developed *C. diff*. eight (8) more times. Each time I was prescribed antibiotics for other, mostly minor infections.

I also developed C. diff. following the use of antibiotics for knee replacement, minor hip surgery, and major back surgery, as well as after antibiotics for a dental procedure.

With each of these infections, I became more ill, and the antibiotics required to treat me were stronger and stronger, and took longer and longer to work.

Like it does to so many others, chronic illness affected every aspect of my life. I was forced to go on long-term disability from my job, and ultimately was approved for Social Security Disability Insurance income due to my inability to work, partly due to the debilitating effects of years of chronic illness from C. diff.

In addition to the personal financial consequences, the economic burden to my health insurer were severe as well. In one calendar year alone, my insurance company was billed \$275,000.00 for one antibiotic alone.

Apart from the physical and financial consequences of my battle with C. diff., the psychological fallout was by far the worst. Each time I was sick, I became more and more isolated due to the infection control measures necessary when dealing with an infectious disease. The symptoms from the disease, in my case diarrhea twenty (20) to thirty (30) times a day, required I remain close to restroom facilities at all times, and also left me too weak and dehydrated to do anything but lie in bed and wait for the next violent attack.

My quality of life became so dismal that I began to wonder if I wanted to go on living this way, with no end in sight. Not only was I becoming weaker and weaker,

but my recovery each time was taking longer and longer, and I would never quite reach the level of health I had before the last infection.

Finally, in 2012, when I contracted C. diff. following one dose of a common antibiotic, amoxicillin, prior to teeth cleaning after a knee replacement, the antibiotics that were available to treat the C. diff. quit working. After months of treatment, with no improvement, I was told I was out of options. There was nothing else left to try. I could have my colon removed, but my surgeon was afraid I was too weak and sick to survive the surgery. Can you imagine dying from an infectious disease that you had fought so hard and for so long, only to be told there was nothing else to be done? Neither could I.

That is the scenario facing more and more people, as the overuse of antibiotics has resulted in bacteria that has evolved to be resistant to our weapons. While we are given the same few classes of antibiotics over, and over, and over again from birth, some bacteria has now become impervious to them. Where do we go from here?

I'm very thankful that one of my three wonderful daughters, looking for options for their desperately ill mother, happened to come across information about something called a fecal transplant. You've probably heard of it by now as it's been getting quite a lot of media attention the last few years. But in 2012, there were only two providers of fecal transplant identifiable in the world through internet research, one in Australia, and one in Reno, Nevada. I was too sick to travel to either one.

I took information about FMT (fecal microbiota transplantation) to each of my physicians, only to be told time and again that they had never heard of the treatment, or, that they had heard of it but would not consider doing it. I had no choice but to do what so many desperately ill people are doing, do a fecal transplant at home. Luckily, one of my doctors agreed for my husband's stool to be tested before the procedure.

Amazingly, just a few hours after receiving a donation of my husband's stool by enema, I felt well enough to shower, dress, and go downstairs for something to eat, all things I had not been able to do for months. If I had not experienced this reaction myself, I would not have believed it was possible. Within two (2) weeks of the fecal transplant, I tested negative for C. diff. Sadly, I had to have emergency back surgery just a few months later, was given prophylactic antibiotics, again to PREVENT infection, only to have those same antibiotics again cause C. diff. This time, however, my colon and rectal surgeon agreed to try fecal transplant by colonoscopy, so I became one of the first people in Indiana to have FMT administered by a physician. And again, by the time I awoke from the sedation for the colonoscopy, I felt almost fine, and tested negative for C. diff. within weeks.

My experience with C. diff. and then with FMT, led me to found The Fecal Transplant Foundation in 2013. I just could not stand the thought that so many people, 500,000 people a year in the U.S. according to the CDC, were being diagnosed with C. diff., and at least 29,000 people a year in the U.S. are dying from this opportunistic infection.

Up to 30% of those diagnosed, or 150,000 people a year, will have a recurrence of the infection and could benefit from, or have their lives saved by fecal transplant, and yet it remains widely unknown and is often difficult to obtain.

Fecal transplant is successful in treating C. diff. about 95% of the time. We have made great strides in the last two years. Our website, [thefecaltransplantfoundation.org](http://thefecaltransplantfoundation.org), has been viewed millions of times. We are working night and day to raise awareness and provide education about this life saving treatment. We now partner with many other foundations and organizations, including the CDC, on the growing problem of antibiotic overuse and conversely, antibiotic stewardship.

Please urge the FDA to remove the tag of “experimental” from the coding for FMT for C. diff., and require insurance companies to cover the procedure. Please urge the FDA to allow FMT for C. diff. to be performed at any time during the treatment process that is mutually agreed upon by the physician and patient, instead of after three failed courses of antibiotic treatment, which would begin saving lives immediately. Please pass legislation that will restrict the use of antibiotics to only bacterial, not viral infections, that will not clear up on their own. Please prevent the addition of antibiotics to our food supply. Please further incentivize pharmaceutical companies to produce new and different classes of antibiotics to which bacteria will not have resistance. Please do all of these things before it’s too late, and you, or I, or your loved one, or all of us, are truly out of options. Thank you.





[www.corpsnetwork.org](http://www.corpsnetwork.org)

*Written Testimony for the Record from: Mary Ellen Sprenkel, President & CEO*

April 29, 2015

The Honorable Tom Cole

Chairman

Subcommittee on Labor, Health and

Human Services, and Education

2358-B Rayburn House Office Building

Washington, DC 20515

The Honorable Rosa DeLauro

Ranking Member

Subcommittee on Labor, Health and

Human Services, and Education

2358-B Rayburn House Office Building

Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro,

We write to respectfully urge your support for the President's Budget Request for the Corporation for National and Community Service (CNCS) for Fiscal Year 2016 and support an increased funding level for CNCS of \$1.46 billion, with funding for AmeriCorps State and National of \$568.1 million, AmeriCorps NCCC of \$35 million, AmeriCorps VISTA of \$108.8 million, National Service Trust of \$322.3 million, Social Innovation Fund of \$70 million, and State Commission Administration of \$24.6 million. Thank you for the opportunity to provide written testimony for the record, and for your work in balancing important programs within your subcommittee's jurisdiction. While there are many critical priorities under your jurisdiction, we know programs like CNCS' AmeriCorps meet some of the most vital public needs, leverage



significant additional private funding and resources, and save the government money in the long run. A recent study put the return on investment in AmeriCorps at 4:1.

The Corps Network (TCN) represents the nation's 100+ Service and Conservation Corps (Corps) as they harness the power of youth and young adults to tackle some of America's greatest challenges and transform their own lives. Corps are comprehensive youth development service program that work in all states and the District of Columbia and enroll around 23,000 youth each year. Corps follow a model of adult mentors (Crewleaders) guiding crews of youth (Corpsmembers, ages 16-25) which perform community and conservation service projects in urban areas or on public lands. Tied to those projects, Corpsmembers receive educational, workforce development, and supportive services. Corps enroll diverse Corpsmembers, and prioritize providing opportunity for disconnected youth to have opportunities to serve in AmeriCorps. In 2013, 60% of TCN Corpsmembers were from families living below the poverty line, 55% were unemployed, 30% were not in school and had no High School Diploma/GED, and nearly 20% were formerly incarcerated or court-involved.

As a result of CNCS' AmeriCorps State and National, AmeriCorps VISTA, and AmeriCorps NCCC, Corps are able to leverage additional match funds to accomplish a wealth of conservation, infrastructure improvement, and human service projects identified as critical by local communities and partners. Corps improve and preserve our public lands and national parks while others provide energy conservation services, including weatherization and alternative energy installation. Some Corps restore natural habitats and create urban parks and gardens. Still



others provide disaster preparation and recovery to under-resourced communities and work on other infrastructure projects like transportation and water infrastructure. Corps also specifically engage veterans in Veterans Conservation and Fire Corps and Native Americans in conservation and restoration projects on tribal land like in Acoma Pueblo and the Navajo Nation.

In particular, The Corps Network urges your support for the Summer Opportunity Youth pilot program the President has proposed in his FY16 CNCS Budget request. According to CNCS' budget justification, the "summer Opportunity Youth initiative... will provide 13,000 summer positions to help connect disadvantaged young people to opportunities to address critical needs through service. Youth will engage in experiential learning that introduces them to service, career exploration, and skill building, all while earning a living allowance and an education award that they can use to help pay for college. AmeriCorps members will focus on activities like rebuilding their communities and helping to restore trust through service in parks – urban and rural, creating safe places to congregate, and addressing the academic summer slide along with other pressing community needs." There is a significant need to reengage disconnected youth, and help them get on a path to furthering their education and into the workforce.

The Corps Network is presently operating a full-time Opportunity Youth Service Initiative with support from CNCS to enroll hundreds of out of school and out of work youth in national service environmental stewardship initiatives at Corps around the country. While serving, they gain career skills, hands on work experience, and advance their education. They also earn AmeriCorps education awards that help encourage them to enroll in postsecondary



education/training. As of 2015, there are approximately 5.8 million young Americans who meet the definition of Opportunity Youth. These young men and women represent a social and economic opportunity: many of them are eager to further their education, gain work experience and help their communities, but need meaningful ways to do so. Not investing in these young people, and those that might be at-risk of fully disconnecting at 14 or 15, means greater cost to taxpayers and society in the hundreds of thousands of dollars later on as they remain disconnected.

CNCS has worked for many years in communities around the country and with non-profit organizations like ours to address the most pressing social challenges with significant buy-in from local public and private entities. We are pleased to be able to participate in new partnerships that CNCS has established through the President's National Service Task Force and urge your support for encouraging more of such partnerships. For example, The Corps Network has been able to enroll court-involved youth in AmeriCorps and partner them with mentors while helping them be seen as an asset to their community, not a liability. Additionally, we've worked with CNCS and the US Department of Agriculture to enroll AmeriCorps members in a 21<sup>st</sup> Century Conservation Service Corps to accomplish important work on public lands and help address the millions of dollars in backlogged maintenance.

As you can see, CNCS supports many important initiatives that engage a diverse population of youth serving in Corps including veterans, Native Americans and individuals with disabilities. In the wake of the recession, it is more important than ever to support this type of work to fill-in the



[www.corpsnetwork.org](http://www.corpsnetwork.org)

gaps of community need. There is also significant demand for these positions, with all of our Corps being oversubscribed and CNCS reporting in 2011, 582,000 AmeriCorps applications were received with only 82,000 slots available. As a result of budget cuts, AmeriCorps slots presently stand at around 71,000 despite this huge demand. Through your support, we can provide more service opportunities for our youth to reengage in education, work, and their communities and get on a productive path for the United States' continued growth and prosperity.

Thank you for the opportunity to provide written testimony for the record. We again respectfully urge your support for the President's Budget Request for CNCS and for increased funding of \$1.46 billion for the Corporation for National and Community Service in Fiscal Year 2016. Thank you for your time and consideration of this testimony.

Sincerely,

A handwritten signature in cursive script that reads "Mary Ellen Sprenkel".

Mary Ellen Sprenkel

President & CEO

Margo Waters

Lead Independent Living Specialist/Housing Advocate

#### disABILITY LINK

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, Centers for Independent Living are an excellent in providing services and keeping people engaged with their communities. disABILITY LINK is dedicated to providing services, information and referral, advocating and supporting consumers to advocate for themselves.

Independent Living Skills and training(s) provide a venue of learning tools. I myself have seen many consumers benefit from the empowerment that they gained as a result from the provided support and services that were received.

Recently a peer prior to becoming an intern at disABILITY LINK had an affordable housing goal. Used the information that was gave to them and was able to find housing that was affordable the housing search process took about six months. With self-determination and advice received from peers this person is now living INDEPENDENTLY in their own apartment..

Another consumer whose goal Personal Resource Management to get a furniture bank referral and receive a voucher. One of the important factor to receiving assistance through this agency is that it's a once in a life time opportunity. To ask "Have you ever received furniture from the furniture bank?" is asked by the ILS as well as being on the furniture bank application.

The application was processed and when the warehouse visit funds were received the furniture bank warehouse manager contacted me by email denying the application. The warehouse manager reported that the consumer had received furniture in the past and would only be eligible for a bed referral.

Consumer was contacted and made aware of the furniture bank's denial. Consumer objected the decision and reported to me that a few years ago she had been an Identity Theft victim. I asked if she had proof and she did.

Consumer visited the furniture bank's manager and provided her self-advocate skills that I encouraged her to use. My consumer was granted a voucher from the furniture bank. I strongly support NCIL's testimony

## Outside Witness Testimony – Fiscal Year 2016 Appropriations

Submitted by

ACT UP Philadelphia; AIDS United; amfAR; Drug Policy Alliance; Harm Reduction Coalition; HealthGAP; HIV Medicine Association; National Alliance of State and Territorial AIDS Directors; National Viral Hepatitis Roundtable; Ryan White Medical Providers Coalition; United Methodist Church, General Board of Church and Society; Urban Coalition for HIV/AIDS Prevention Services

Contact: Christine Rodriguez, Public Policy Manager  
National Viral Hepatitis Roundtable, [crodriguez@nvhr.org](mailto:crodriguez@nvhr.org)

Prepared for

The United States House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 29, 2015

The National Viral Hepatitis Roundtable, on behalf of the above listed organizations, respectfully submits this testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS) regarding the Fiscal Year (FY) 2016 Appropriations budget hearing. As a coalition representing HIV/AIDS, viral hepatitis, drug policy, and faith-based organizations, among others, we are gravely concerned about the public health consequences created by the restriction of federal funds to local health agencies for prevention programming through syringe services programs (SSPs). The following cost-neutral request concerns policy riders included in General Provisions, impacting the Centers for Disease Control and Prevention (CDC).

Recent headlines such as “Indiana calls in CDC to help with HIV outbreak” should resonate with Members of this Subcommittee with jurisdictional oversight of prevention programs. As of April 17<sup>th</sup>, there were 120 confirmed and 10 preliminary positive cases of HIV from the sharing of drug injection equipment in Indiana along the Kentucky border.<sup>1</sup> In fact, Governor Pence (R-IN) declared a

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<sup>1</sup>[http://www.in.gov/activecalendar/EventList.aspx?eventidn=218148&view=EventDetails&information\\_id=213578&forcedredirect=Y](http://www.in.gov/activecalendar/EventList.aspx?eventidn=218148&view=EventDetails&information_id=213578&forcedredirect=Y) (Last accessed 4/28/15)

public health emergency and issued an executive order allowing for the operation of an SSP to help reduce the transmission of blood borne disease.

*We therefore urge the Subcommittee to prevent policy riders prohibiting the use of federal funds for any program for the purpose of distributing needles or syringes for the purpose of preventing the spread of blood borne pathogens from the FY2016 LHHS Appropriations Bill.* Such language prohibits state public health authorities from using existing federal prevention funding for SSPs which prevent disease transmission, do not encourage drug use or increase crime, promote public safety, and connect participants to healthcare and social services, including drug treatment.

Eliminating the ban 1) receives broad national and international support, 2) supports public and law enforcement safety, 3) provides for desperately-needed and highly-effective HIV and hepatitis C prevention among people who inject drugs (PWID), and 4) is a cost-neutral policy change supporting cost-effective interventions.

### **Broad Support**

Despite the persistence of the ban on federal funds for syringe access, SSPs enjoy broad support from many professional and public health entities. Supportive U.S. government entities include CDC, the Substance Abuse and Mental Health Services Administration, U.S. Surgeon General, National Institutes of Health, and the White House Offices of National AIDS Policy and National Drug Control Policy. US-based organizations supporting syringe access include: the American Medical Association, American Public Health Association, National Academy of Sciences, American Academy of Pediatrics, American Nurses Association, American Bar Association, U.S. Conference of Mayors, and the Infectious Diseases Society of America. Supportive global entities include: the World Health Organization, World Bank, and the International Red Cross-Red Crescent Society.



It is long past time to treat syringe access for what it is – a critical component of any comprehensive response to the interconnected epidemics of opioid and heroin addiction, HIV/AIDS, hepatitis C, and overdose which have gripped the nation.

### **Supporting Public and Law Enforcement Safety**

SSPs do much more than provide sterile syringe access. A practical service SSPs provide, thanks to the trust established among PWID, is used syringe collection and disposal. Fear of arrest or incarceration for possession of syringes (considered illegal drug paraphernalia by many states), can result in improper disposal or failure to disclose possession if stopped by law enforcement. When SSPs provide safe disposal, the majority of syringes distributed are returned. Safe disposal reduces the risk of accidental needlestick injuries for the public, whether children playing in parks or first-responders at a medical emergency. SSPs' safe disposal services also reduce police officers' risk of needlestick injuries, an occupational hazard concerning many officers and their families. Finally, there is no evidence supporting the assertion that SSPs increase either crime or drug use.

### **Effective Infectious Disease Prevention**

SSPs have been proven over the last 20 years to be highly effective at reducing HIV and hepatitis C transmission,<sup>2</sup> two viruses that disproportionately impact PWID. Many also provide services such as HIV and hepatitis C testing, overdose prevention training, referrals to social services and housing, and linkage to medical care, mental health care, and drug treatment for those not often served by traditional health care providers. SSPs are a crucial support for PWID at every point along the continuums of care for HIV and hepatitis C. The District of Columbia exemplifies this – when Congress lifted a similar ban barring the District from using its local dollars on SSPs in 2007, the DC

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<sup>2</sup> <http://www.who.int/hiv/pub/ida/poibidu/en/>

Department of Health expanded syringe access services and subsequently reported an 81% decrease in new HIV infections among PWID from 2008-2012.<sup>3</sup>

It is a critical time to support SSPs as a tool in addressing the hepatitis C and HIV epidemics. As Americans nationwide are devastated by the crises of prescription opioid addiction and overdose, the trend – particularly among youth under 30 in non-urban communities – begins with misuse of oral opioid painkillers, to experimenting with injecting, followed often by a transition to heroin. Directly on the heels of this crisis is a new wave of the hepatitis C epidemic, with CDC reporting a 75% increase in new cases from 2010-2012<sup>4</sup> (likely a significant underestimate due to lack of surveillance infrastructure). In response to the overwhelming burden of hepatitis C in this context, the Kentucky State Legislature passed a comprehensive bill to address these issues in March 2015, legalizing SSPs as part of its package of legislation.

With overlapping modes of transmission, HIV often follows in hepatitis C's tracks, and Indiana is the first to see a large outbreak of HIV among a network of people injecting an opioid painkiller. As mentioned above, Gov. Pence declared the outbreak a public health emergency, with a temporary allowance for SSPs in the county where it occurred. This was a critical step in the right direction, but for SSPs to be truly impactful, they must be legal, widespread, and fully resourced. New York achieved a major reduction in HIV/AIDS from 1992, when 52% of AIDS cases were attributed to injection drug use, to 2004, when only 5.4% of HIV cases were so attributed. The Department of Health credits the Syringe Exchange and Expanded Syringe Access Program with the state's remarkable results.<sup>5</sup>

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<sup>3</sup> [http://doh.dc.gov/sites/default/files/dc/sites/doh/page\\_content/attachments/Newly%20Diagnosed%20HIV%20Cases.pdf](http://doh.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/Newly%20Diagnosed%20HIV%20Cases.pdf), p17

<sup>4</sup> <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm#hcv>

<sup>5</sup> <http://www.health.ny.gov/diseases/aids/general/about-prevention.htm#harmred>

Finally, it is vital to acknowledge SSPs' pioneering role in naloxone access for overdose prevention. SSPs remain uniquely positioned not only to reach PWID with prevention and screening for HIV and hepatitis C, but also to continue to lead the field in overdose prevention, thanks in large part to the positive relationships built with traditionally hard-to-reach communities.

### **Cost-Neutral and Cost-Effective**

The ban on federal funds for SSPs takes the form of an annual General Provisions policy rider in the LHHS Appropriations bill. Removing the ban language – or replacing it with verbiage affirming the use of federal funds for SSPs – is entirely cost-neutral, requiring no offset. Providing sterile syringes to PWID is proven to be highly cost-effective. For every dollar invested in syringe access, approximately \$3-8 in HIV treatment are saved. This does not take into account further savings from averted hepatitis C infection, avoiding increased healthcare expense due to living with the virus without treatment, treatment costs, or the expensive potential consequences of chronic hepatitis C – end-stage liver disease, liver cancer, and/or liver transplants.

Despite the ban on using federal funds for SSPs, 33 states, the District of Columbia, and Puerto Rico have made local investments to support the preventive value of SSPs as of June 2014<sup>6</sup> – a growing number as evidenced by Kentucky's recent legislation legalizing SSPs mentioned previously. Federal grant funding would provide vital support to ensure the sustainability of SSPs, as states increasingly elect to include this intervention among their comprehensive prevention plans.

Again, we strongly urge the Subcommittee to prevent policy riders prohibiting the use of federal funds for syringe access in the FY2016 LHHS Appropriations bill. We thank Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee for their thoughtful consideration of our request.

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<sup>6</sup> [http://www.amfar.org/uploaded\\_files/amfarorg/Articles/On\\_The\\_Hill/2013/2013%20SSP%20Map%20Final.pdf](http://www.amfar.org/uploaded_files/amfarorg/Articles/On_The_Hill/2013/2013%20SSP%20Map%20Final.pdf)

**Outside Witness Testimony – Fiscal Year 2016 Appropriations**

Submitted by  
Christine Rodriguez, Public Policy Manager, [crodriguez@nyhr.org](mailto:crodriguez@nyhr.org)  
National Viral Hepatitis Roundtable

Prepared for  
The United States House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 29, 2015

The National Viral Hepatitis Roundtable (NVHR) respectfully submits this testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS) regarding the Fiscal Year (FY) 2016 Appropriations hearing. As a broad national coalition representing over 200 organizations committed to fighting, and ultimately ending, the hepatitis B and hepatitis C epidemics, we are gravely concerned about the missed opportunities and negative public health consequences resulting from the lack of resources to adequately address these two communicable viruses in the United States. *We therefore urge the Subcommittee to increase the allocation for the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention (CDC) to the full \$62.8 million requested by the Administration for FY2016*, an increase of \$31.3 million over FY2015.

Further, particularly due to the steep rise in hepatitis C cases that is interconnected with the opioid and heroin addiction crisis, *we also urge the Subcommittee to prevent policy riders prohibiting the use of federal funds for any program for the purpose of distributing needles or syringes for the purpose of preventing the spread of blood borne pathogens from the FY2016 LHHS Appropriations Bill*, a cost-neutral request, given the critical role syringe services programs (SSPs) play in hepatitis C prevention, screening, and linkage to healthcare and drug treatment. For

more detailed information regarding the ban on federal funds for SSPs, please see separate testimony on the issue submitted by NVHR and allied organizations to this Subcommittee.

This request is especially urgent given: 1) the vital need for robust surveillance infrastructure; 2) the overwhelming contribution of hepatitis B and C to the rising incidence of liver cancer; and 3) the state of the hepatitis C epidemic, with unique challenges in tackling prevalence and incidence, and tremendous opportunity created by new curative treatment.

### **Scope of the Epidemics**

Despite a safe, effective vaccine for hepatitis B, and new curative treatments for hepatitis C, CDC conservatively estimates that approximately 1.4 million Americans are living with chronic hepatitis B, and 3.2 million are living with chronic hepatitis C.<sup>1</sup> These are likely underestimates however, as surveillance systems nationwide are disjointed at best, with only five states and two jurisdictions (Florida, Massachusetts, Michigan, New York, Washington, Philadelphia, and San Francisco) federally funded for such activities.<sup>2</sup> Of primary concern is that of the nearly 5 million individuals thought to be living with hepatitis B and/or C, up to 75% do not know they are infected with a potentially life-threatening and communicable virus, as both hepatitis B and C are most often asymptomatic until the liver is already significantly damaged.<sup>3</sup> On average, hepatitis B and/or C will shorten one's lifespan by 15-20 years.<sup>4</sup>

There are substantial disparities among various communities for both viruses as well. While comprising less than 5% of the U.S. population, Asian American and Pacific Islander communities comprise over 50% of all hepatitis B prevalence.<sup>5</sup> As hepatitis B is endemic in many regions of the

<sup>1</sup> <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm>

<sup>2</sup> [http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations\\_budget\\_form.pdf](http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations_budget_form.pdf) FY2016\_CDC\_CJ\_FINAL.pdf, p. 85-91.

<sup>3</sup> [http://www.cdc.gov/fmo/topic/budget%20Information/FY-2016-Fact-Sheets/FY2016\\_Pres\\_Budget\\_Final\\_VIHHMP.pdf](http://www.cdc.gov/fmo/topic/budget%20Information/FY-2016-Fact-Sheets/FY2016_Pres_Budget_Final_VIHHMP.pdf)

<sup>4</sup> <http://cid.oxfordjournals.org/content/58/8/1047.full.pdf+html>

<sup>5</sup> <http://www.cdc.gov/hepatitis/Populations/api.htm>

world, particularly Asia and Africa, the foreign-born and their children are also at risk.<sup>6</sup> Many diverse communities are highly and disproportionately impacted by hepatitis C compared to the general population, including veterans, especially Vietnam-era service members; the “baby boomer” birth cohort (born 1945-1965); communities of color, including tribal communities; the incarcerated/returning citizens; and people who inject drugs.

### **Strengthening Surveillance**

Surveillance – the “continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice”<sup>7</sup> – is the core public health service driving effective interventions, and particularly vital for infectious disease. The current surveillance system for hepatitis B and C is woefully underfunded, so available data offers merely a snapshot of the epidemics, albeit an alarming one. Without significantly bolstering states’ ability to leverage existing systems of surveillance, the epidemics will stay ahead of our efforts to eliminate them – a goal achievable in coming decades with dedicated resources. CDC’s Division of Viral Hepatitis has identified strengthening surveillance as one of its primary strategic goals given an increase in appropriations.<sup>8</sup>

### **Hepatitis B, Hepatitis C, and Liver Cancer**

Liver cancer is one of the potential long-term consequences of chronic hepatitis B and C, and among the most aggressive and deadliest cancers with a devastatingly low 15% five-year combined survival rate.<sup>9</sup> Despite a downward trend in the incidence of many cancers, we unfortunately see the reverse with liver cancer where rates are rising. In fact, hepatitis C infection alone leads all causes of

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<sup>6</sup> Ibid.

<sup>7</sup> [http://www.who.int/topics/public\\_health\\_surveillance/en/](http://www.who.int/topics/public_health_surveillance/en/)

<sup>8</sup> [http://www.cdc.gov/imo/topic/Budget%20Information/appropriations\\_budget\\_form\\_pdlFY2016\\_CDC\\_CJ\\_FINAL.pdf](http://www.cdc.gov/imo/topic/Budget%20Information/appropriations_budget_form_pdlFY2016_CDC_CJ_FINAL.pdf), p. 85-91.

<sup>9</sup> <http://www.cancer.org/cancer/livercancer/detailedguide/liver-cancer-survival-rates>

liver cancer.<sup>10</sup> Not only can the debilitating consequences of hepatitis B and C be avoided – with vaccination for hepatitis B and curative treatment for hepatitis C – addressing these epidemics can serve the secondary purpose of preventing a substantial proportion of primary liver cancer cases.

### **Hepatitis C – Unique Challenges and Opportunities**

The hepatitis C epidemic exists in two fairly distinct waves. The majority of prevalence is among the baby boomer birth cohort, who comprise about 75% of those currently living with hepatitis C. While this population by and large is not transmitting the virus, the majority do not know they are infected and have likely been living with hepatitis C for decades. As this community ages, hepatitis C's long-term impacts will become more apparent as patients increasingly present with cirrhosis (scarring) of the liver, end-stage liver disease, liver cancer, and the need for liver transplants. A recent study suggests that nearly half of baby boomers with hepatitis C already have severe liver scarring and need immediate treatment.<sup>11</sup> As they rapidly age into Medicare, it is vital to identify those living with hepatitis C and link them to appropriate care and treatment.

A second emerging wave of the epidemic drives current transmission. As Americans nationwide are devastated by the current crisis of prescription opioid addiction – particularly among youth under 30 in rural and suburban communities – the trend begins with misuse of oral opioid painkillers, to experimenting with injecting, followed often by a transition to heroin.<sup>12</sup> Directly on the heels of this crisis is a new, sustained spike in hepatitis C, with CDC reporting a 75% increase in new cases from 2010-2012<sup>13</sup> (likely a significant underestimate due to lack of surveillance infrastructure, as discussed above). While new infections in just three states – Tennessee, West

<sup>10</sup> [http://www.cdc.gov/fmo/topic/budget%20information/FY-2016-Fact-Sheets/FY2016\\_Pres\\_Budget\\_Final\\_VHIMP.pdf](http://www.cdc.gov/fmo/topic/budget%20information/FY-2016-Fact-Sheets/FY2016_Pres_Budget_Final_VHIMP.pdf)

<sup>11</sup> <http://www.hivandhepatitis.com/hepatitis-c/hepatitis-c-topics/hcv-disease-progression/3086-enrol-2015-liver-disease-progression-is-common-among-baby-boomers-with-hepatitis-c>

<sup>12</sup> <https://www.aids.gov/pdf/hcv-and-young-psw-id-consultation-report.pdf>

<sup>13</sup> <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm#hepC>

Virginia, and Kentucky – comprise 20% of overall incidence, a distressing 35 of 41 states reporting data to CDC saw increases in hepatitis C infection rates.<sup>14</sup> States urgently need existing federal prevention grant funding to utilize and sustain syringe services programs as part of a comprehensive prevention response; lifting the ban on the use of federal funds for SSPs is a crucial and cost-neutral policy fix.<sup>15</sup>

Despite the many challenges in catching up to this epidemic, it is also a time of tremendous opportunity for those living with hepatitis C. In the past several years, new direct-acting antivirals entered the market, with cure rates over 90%, far shorter regimens, and few to no side effects compared to previous treatments. With this medical innovation has come hope for millions, and a cure can be offered to those who test positive. Although these new options have revolutionized hepatitis C treatment, there are a number of natural barriers to treating everyone who needs it; most significantly, up to 75% of those living with hepatitis C do not know it as most will not experience symptoms, and there is a significant lack of provider capacity. Building the capacity of providers and scaling efforts to identify those with hepatitis C are among DVH's strategic priorities given a modest increase in resources.

Again, we strongly urge the Subcommittee to increase the allocation for CDC's DVH to \$62.8 million for FY2016, an increase of \$31.3 million over FY2015, as well as to prevent policy riders prohibiting the use of federal funds for syringe access in the FY2016 LHHS Appropriations bill. We thank Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee for their thoughtful consideration of our request.

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<sup>14</sup> <http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm>

<sup>15</sup> Please see separate testimony on this issue submitted by NVHR and allied organizations to this Subcommittee.





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**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)

I write today to submit testimony for the record demonstrating the work of the Office of Protection and Advocacy for Persons with Disabilities, the Protection and Advocacy (P&A) agency for Connecticut on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights

and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

In 2014, the Connecticut Office of Protection and Advocacy for Persons with Disabilities served 122 individual clients, participated in 86 training and outreach events that reached more than 1,600 people, and provided informational and referral services to an additional 3,447 people. In addition to these activities, there were 148,260 hits on the website and 178,000 people were impacted by the activities undertaken by the Office of Protection and Advocacy for Persons with Disabilities on behalf of groups of clients.

As an example of the work done by the Connecticut Office of Protection and Advocacy for Persons with Disabilities concerning community integration and accessing services for people with intellectual and developmental disabilities, below is an example of our work from 2014.

#### **Example 1 – At Home with Nilda**

On a rainy morning, the movie, “Heidi,” plays on the television in the living room of a group home. Two women watch. Garlands of orange artificial flowers and autumn-themed figures of straw and cloth decorate the windows and walls. Natural light floods the space, which is open, welcoming and clean. One of the women is Nilda, and this is her new home.

Nilda had been placed at Southbury Training School in 1970, when she was in her early twenties and a doctor advised the placement. Until then, she had lived with family

members. Her family, constrained by distance and circumstances, rarely saw her. Also constrained was Nilda's institutionalized life, which lacked privacy, enrichment and choice. Even in 2014, she shared a room with three other women.

In March, 2012, a P&A advocate was assigned to work with Nilda and her family. The goal? To find a placement for Nilda in advance of what the family was told would be Southbury's eventual closing. The parents worried at first: Would she be safe? Would she adjust after spending most of her adulthood in an institution? "This would be a new beginning," the advocate said. "I understood their fears." The advocate spoke their language and shared their culture, enabling her to develop a relationship based on shared identity. (Her relationship with Nilda flourished, too, based not only on the advocate's warmth and cultural affinity, but on Nilda's delight that they were both wearing red nail polish at their first meeting!)

Once the family and Nilda agreed, the advocate shepherded the transitional planning, in the process educating both Southbury and group home staff on the cultural components of some of Nilda's behavior. Previously, for example, Nilda had been labelled physically and verbally aggressive when, in fact, her physicality and the pitch of her voice were often just culturally expressive.

The manager at Nilda's new home says that the adjustment period was remarkably swift and smooth. To ease the transition, Nilda visited the group home several times over the course of six weeks, sharing meals and enjoying overnights. After she moved in, staff

members worked to relieve her of some of the habits and anxieties that had been generated by institutionalization. She used to take the jewelry and hair ornaments of others; now that she has her own special items, she no longer takes them from other rooms. She is learning to differentiate between friends and strangers, both in terms of offering affection and taking basic security measures. She is less likely to layer clothes – sometimes six articles at a time – because she has learned that her clothing will no longer disappear. Nilda's family, says the manager, "is flabbergasted at how much the group home will work with them," providing transportation for routine visits and holidays. Nilda, recently met a much younger brother for the very first time.

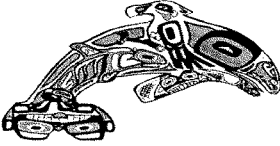
Nilda's bedroom – *hers alone* – has a bed covered in a brightly patterned comforter; it is meticulously made, the result of her own daily effort. Inside the room are decorative items on the wall; a closet; a CD player; a TV; and a bureau filled with clothes and personal items, including the many self-made art pieces that Nilda, left to her own devices, would never recycle, give as gifts, or throw away. On the bed, leaning against the pillows, are two dolls, carefully dressed. The house manager playfully lies on the bed, resting against them; in response, Nilda promptly and with good humor pulls the manager off the bed and adjusts the hat on one of the dolls. Just so.

As part of her day program, Nilda works twice a week at Chili's, rolling silverware in napkins in preparation for tables. Once a week, she volunteers at a nature center, watering the plants. Twice a week, she participates in music appreciation events, singing, dancing and trying out instruments. At home, one of her chores, enthusiastically

embraced, is to fold her laundry, which she does every morning. She strings beads into necklaces. She participates in the daily dance parties at the house. She is eager to help staff members with household jobs.

On the TV, a monkey is causing major shenanigans, leaping from a chandelier and irritating the villain in the story. Nilda and her friend dissolve into laughter at the slapstick. Two women, completely attuned to the nuances of human emotion, enjoying a movie at home on a rainy day.

Thank you for the opportunity to submit this testimony.



## Squaxin Island Tribe

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**Written Testimony Submitted by Councilman Jim Peters, Squaxin Island Tribe  
Submitted to the House Labor, Health and Human Services, Education and Related  
Agencies Appropriations Subcommittee  
On the Fiscal Year FY 2016 Budget for the  
Substance Abuse and Mental Health Services Administration  
April 29, 2015**

On behalf of the Tribal Leadership and citizens of the Squaxin Island Tribe, I am honored to submit our requests to this Subcommittee for appropriations to address the un-funded needs of American Indian and Alaska Native Treatment (AI/AN) Centers. The alarming statistics of increased alcohol and substance abuse in AI/AN communities speak volumes to the need for improved and additional facilities to provide treatment and recovery services to our citizens, our youths, our future leaders and the next seven generations. Although Substance Abuse and Mental Health Services Administration (SAMHSA) has limited discretionary funding and even fewer resources for residential care facilities, the Indian Health Service (IHS) cannot keep pace with the growing need for these treatment centers. The only funding opportunity available in SAMHSA is the Treatment for Pregnant and Postpartum Women. **In 2016, we respectfully request that the Subcommittee considers the following requests:**

1. \$10 million - Expand access to residential care facility appropriations to include Treatment Centers and increase the annual appropriations to supplement inadequate funding for these centers from the Indian Health Service, of which the NWITC will receive \$1.5 million;
2. \$50 million - SAMHSA's Behavioral Health Tribal Prevention Grant Program (\$45 million increase over the FY 2015 enacted level);
3. Request full funding for streamlined implementation of the Patient Protection and

**Affordable Care Act and the Indian Health Care Improvement Act;**

**4. Restore funding to \$280 million for Child Welfare Services (Social Security Act Title IV-B, Subpart);**

**5. Substance Abuse and Mental Health Services Administration – Circles of Care Program \$6 million for Tribal and Urban Indian Communities;**

**6. Substance Abuse and Mental Health Services Administration – American Indian and Alaska Native (AI/AN) Suicide Prevention – Restore funding to FY2012 level of \$2.97 million to ensure that there is adequate assistance available to Tribal communities working to support the mental health of AI/AN youth.**

**7. The Squaxin Island Tribe Supports the requests of the Northwest Portland Area Indian Health Board, National Indian Health Board and the National Congress of American Indians.**

**Self-Governance** is the most successful policy in the history of Tribal – Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination and to design facilities, manage programs and funds, and provide services that are responsive to the needs of our communities and Tribal citizens. Self-Governance Tribes have made every attempt to be innovative to operate successful health programs given the budget constraints and cuts Tribal programs have incurred the past two decades. We request that this Committee recognizes the success of Self-Governance and encourage HHS to work with Tribes to make the most efficient and effective use of Federal appropriations for Tribal programs.

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**The Squaxin Island Tribe** has been operating the Northwest Indian Treatment Center (NWITC) since 1994. Ingenious in creativity, the center offers a wide variety of cultural activities and traditional/religious ceremonies, making it a natural place to heal - body, mind and soul. Fittingly, the center was given the spiritual name “D3WXbi Palil” meaning “Returning from the Dark, Deep Waters to the Light.” NWITC is a residential chemical dependency treatment facility designed to serve American Indians from Tribes located in Oregon, Washington and Idaho who have chronic relapse patterns related to unresolved grief and trauma. NWITC is unique in its integration of Tribal cultural values into a therapeutic environment for co-occurring substance abuse and mental health disorders. It is a 28 bed, 30-60 day residential facility.

**1. \$10 Million - Expand Access to Residential Care Facilities Appropriations to supplement inadequate funding for these centers from the Indian Health Service** - Welcomed and hailed by Tribal Leaders who felt the urgent need for such a facility, the Northwest Indian Treatment Center (NWITC) is centrally located in Grays Harbor County between Olympia and Aberdeen, on 2.5 acres in the small rural town of Elma, Washington. NWITC accepts patients that are referred through outpatient treatment programs, parole and probation services, hospitals, assessment centers and child and family service centers. Medical care is provided through local Indian Health Service clinics and other medical service providers. NWITC has responded with an overwhelming success rate of nearly 65 percent.

Since the original Congressional set-aside in 1993, NWITC has not received an adequate increase in the base Indian Health Service budget. It is critical to increase the NWITC’s annual base in order to sustain the current services to the Tribes of the Northwest. **An increase of \$1.5 million would restore lost purchasing power and meet the need to add mental health and**



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**psychiatric components to the treatment program.** This increase would allow NWITC to continue its effective treatment of Native Americans.

The Treatment Center's traditional foods and medicines program is supported through a partnership with the Northwest Indian College and is funded through grants from the Washington Health Foundation, the National Institute of Food and Agriculture, The Potlatch Fund and several Tribes. Weekly hands-on classes focus on traditional foods and medicines, including methods for growing, harvesting, processing, and preparation. Twice a month, Tribal elders, storytellers, and cultural specialists speak as part of the program. A monthly family class allows patients to share what they are learning with their loved ones. Patients gain hands-on experience by working in three on-site teaching gardens. This program serves as a model for other Tribal communities.

**2. \$50 million - SAMHSA Behavioral Health - Tribal Prevention Grants Program (\$45 million over FY 2015 request level)** - Behavioral health remains one of Indian Country's most pressing needs yet it remains one of the most undervalued and least-addressed issues in the 21<sup>st</sup> Century. This program was developed to address the importance of emotional health, prevention and health promotion for Indian people and Tribes who choose to apply could develop a comprehensive plan. This planning activity is one of the basic components of the Tribal Law and Order Act (TLOA) and the Indian Alcohol and Substance Abuse Act, which SAMHSA is charged to coordinate in statute.

**3. Request full funding for streamlined implementation of the Patient Protection and Affordable Care Act and the Indian Health Care Improvement Act - Request funding increases to begin implementing the twenty-five unfunded provisions in IHCA and countless others in the ACA** each representing an unleveraged opportunity to increase and

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improve services for American Indians and Alaska Natives across the Nation. Health reform represents a significant opportunity for Tribal and IHS programs to sustain, improve, and build innovative health systems in Tribal communities. Successful implementation of the law is of great importance to Tribes and hinges on the full funding of the permanent reauthorization of the IHCIA and the overarching Affordable Care Act.

**4. Restore funding to \$280 million for Child Welfare Services (Social Security Act Title IV-B, Subpart) -** The Child Welfare Services Program provides funds that support child welfare program flexibility in the provision of community-based child welfare services. Tribes are eligible for this funding based a formula grant. This Tribal allocation is deducted from the state's allocation.

**5. Substance Abuse and Mental Health Services Administration – Circles of Care Program - Ensure that \$6 million under this line item continues to be reserved specifically for the Tribal and Urban Indian community Circles of Care Program.** The Circles of Care program is the only SAMHSA grant program that is focused specifically on children's mental health issues in Native communities. It is also the only SAMHSA program that allows Tribes and Tribal organizations to apply without competing for funding with other governmental entities like states, counties, or cities.

**6. Substance Abuse and Mental Health Services Administration – American Indian and Alaska Native (AI/AN) Suicide Prevention -** This line item supports training and technical assistance to help Tribal communities mobilize existing resources to target issues that affect mental well-being in youth.

**Thank you for this opportunity to submit written testimony.**



**Testimony Prepared by Karen Pearl, President & CEO of God's Love We Deliver for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

God's Love We Deliver is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 1.3 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase

absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare

costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

### **Conclusion**

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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Hearing on House Appropriations

Subcommittee on Labor, Health & Human Services, Education and Related Agencies

April 29, 2015

Statement for the Record

Amie Lulinski, PhD, Director, Rights Policy

The Arc of the United States

**Submitted by email: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)** (Subject Line: FY 2016 written testimony for the record)

The intent of this written testimony is to express The Arc's strong support for continued appropriations to the Department of Health and Human Services for activities which promote community integration for individuals with disabilities.

With nearly 700 state and local chapters nationwide, The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities (I/DD) and their families. The Arc was founded in 1950 by parents of children with I/DD who wanted their children to lead fulfilling lives in their home communities, not shuttered away in the institutions that were typically the only services available at the time. It was in that spirit that The Arc was born. Today we continue to promote and protect the human rights of people with I/DD and actively support their full inclusion and participation in the community throughout their lifetimes.

The Arc requests the Subcommittee's support for continued appropriations to the Department of Health and Human Services (HHS) for activities which promote community integration for individuals with disabilities. HHS supports a number of critical programs for full inclusion of persons with I/DD, which are widely supported and critically important to improving the lives, independence and well-being of individuals with disabilities.

We oppose efforts to prohibit the use of HHS funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is not only extremely troubling, but counter to the Supreme Court's 1999 landmark decision in *Olmstead v. L.C.*

The nationwide trend of deinstitutionalization began decades ago, gradually turning around the tragic practice of tearing people away from their families and communities in order to provide them with services. In fact, since peaking in 1967, census reduction of institutions has occurred at an average rate of 4% nation-wide annually, resulting in the closure or in-process closure of 173 public institutions in 43 states<sup>1</sup>. This "trend" is a movement that cannot, and should not, be stopped. The vast majority of people want to receive services and supports in their own homes and communities near family and friends, not in isolated institutions far from the lives and people they love and care about. In fact, Congress has a long history of oversight of institutional issues. In 1985, Senator Lowell Weicker Jr. (R-CT) chaired joint hearings<sup>2</sup> of the Senate Committee on Appropriations and the Senate Committee on Labor and Human Resources

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<sup>1</sup> Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., and Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities, Department of Psychiatry, and Department of Disability and Human Development, UIC.

<sup>2</sup> U.S. Government Printing Office (1985). *Examining the Issues Related to the Care of the Nation's Institutionalized Mentally Disabled Persons*. Joint Hearings before the U.S. Senate Subcommittee on the Handicapped of the Committee on Labor and Human Resources and the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, Committee on Appropriations. Retrieved April 28, 2014 from: <http://files.eric.ed.gov/fulltext/ED263712.pdf>

related to the “care and treatment of institutionalized mentally disabled persons” (sic) which was a precursor to the ADA which led to the 1999 Supreme Court’s decision in *Olmstead v. LC*.

In addition, rebalancing expenditures from state operated institutions to smaller community-based settings is sound economic policy. For the average cost of one individual served in a state operated institution, five persons could be served in the community. This system rebalance would assist in addressing the over 322,000 individuals with I/DD who are on a waiting list for home and community based waiver services<sup>3</sup>.

Ultimately, all people benefit when persons with disabilities, including persons with I/DD, are included in community life. People with disabilities should be welcomed and included in all aspects of our society, and like all Americans, they have a right to live in their own homes, in the community. As noted in The Arc’s most recent position statement on Housing, adopted by our Congress of Delegates in 2012, “Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with I/DD, regardless of type or severity of disability. Public policy should promote small, typical living situations for people with I/DD.” In accordance with our mission, values, and positions, The Arc has long supported the Americans with Disabilities Act and its integration mandate.

The U.S. Supreme Court’s decision in *Olmstead v. LC*, 527 U.S. 581 (1999) applied the integration mandate of the Americans with Disabilities Act to state supported and operated living arrangements. The Court held that the ADA prohibits unjustified segregation of individuals with disabilities. *Olmstead* is a landmark decision in the history of the effort of people with I/DD to move out of unnecessary institutions into communities. The work of the Department of Justice (DOJ) in enforcing the *Olmstead* decision is critical and must not be undermined. This non-

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<sup>3</sup> Waiting Lists for Medicaid Section 1915(c) Home and Community-Based Services Waivers <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/>

partisan enforcement began under President George Bush and continues under President Barack Obama.

Enforcement of the ADA's integration mandate and the *Olmstead* decision continues to be a top priority for the disability community. The DOJ's enforcement efforts in recent years have brought some of the most significant improvements to the lives of people with disabilities in decades. As a result, thousands of individuals with disabilities have, for the first time, been given opportunities to live in their own homes and communities, with privacy, dignity, and independence. They have been able to participate as full members of society. The DOJ's enforcement efforts in this area have received overwhelming support from the disability community.

Neither *Olmstead* enforcement nor implementation of the Medicaid home and community-based services (HCBS) settings rules deprives anyone of the choice to live in an institution. On the contrary, *Olmstead* and the settings rules offer thousands of individuals and their families the *option* of choosing home and community-based service settings. No one is forced to move to a community setting against his or her wishes.

Inclusion of any language prohibiting use of Congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice, forcing them to live and receive services in restricted and segregated settings. We urge you to reject this language in the appropriations bill. People with disabilities have fought hard for decades for the opportunity to live, work, and receive services in integrated settings. We respectfully ask that you refrain from acting in any way which would remove community-based options.



**U.S. House of Representatives Committee on Appropriations**

**Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**FY-2016 Appropriations Testimony for the  
Department of Labor, Department of Health and Human Services &  
Department of Education**

**Written Testimony of  
The Honorable W. Ron Allen, Tribal Chairman/ CEO  
Jamestown S'Klallam Tribe  
April 29, 2015**

On behalf of the Jamestown S'Klallam Tribe, I am pleased to submit this written testimony on our funding priorities and requests for the Fiscal Year (FY) 2016 Department of Labor (DOL), Department of Health and Human Services (HHS) and Department of Education (DOE) budgets. Funding for Indian country is appropriated in the non-defense discretionary portion of the Federal budget. We, therefore, renew our request that Congress work together to achieve a balanced approach to the budget deficit that includes raising new revenue sources and that doesn't rely solely on cuts to discretionary spending.

We strongly support the Administration's FY2016 Budget Proposal as it reflects an improved commitment on behalf of the Federal government to uphold treaty and trust obligations with an investment in Indian programs. These proposed increases are extremely important to Tribes because we rely on this funding to support our core governmental programs and critical services that promote the safety and well-being of our Tribal citizens and Indian community. We also advocate for the expansion of Self-Governance so that Tribes can continue to have the

flexibility to redesign programs and services throughout the Federal government to better address their community needs.

In addition to the items detailed below, our Tribe would like to reiterate that we are a direct beneficiary of the collective and continuing efforts of the **National Congress of American Indians, the National Indian Education Association, the Affiliated Tribes of Northwest Indians and the Northwest Portland Area Indian Health Board.**

**TRIBAL SPECIFIC BUDGET PRIORITIES:**

**Department of Labor, Department of Health and Human Services & Department of Education**

- 1. Administration on Aging, Title VI – provide \$30 million (HHS)** - The Administration on Aging Older Americans Act funds a majority of Jamestown's Elder Programs. We use these funds to provide nutrition, health education and to reduce isolation through community and cultural activities which directly impact the health and well-being of our Tribal elders. The care of elders is a culturally inherent responsibility that provides an important part of maintaining our cultural knowledge and wisdom to strengthen our families and communities.
- 2. Head Start – provide \$9.6 billion (HHS)** - Head start provides early educational services to over 24,000 Native children. Many of Jamestown's children partake in the Head Start program. This program provides Federal dollars to support comprehensive services (education, health and family services) that model traditional Native learning and prepare our Tribal youth for Kindergarten by improving conditions necessary for success in education. Quality early childhood education plays a critical role in the health and educational success of our Native students.
- 3. Title VII Indian Education – provide \$198 million (DOE)** - Over 160 American Indian and Alaska Native children have been identified in the Sequim School District. Title VII Indian Education funds allow our staff to provide a culturally sensitive voice to the local school program

which has resulted in increased proficiency scores and an increase in the graduation rate of our American Indian and Alaska Native students.

#### **4. Employment and Training Administration, Indian and Native American Programs -**

**(INAP) –provide \$65 million (DOL) -** The Western Washington Indian Employment and Training Program (WWIETP) consist of a consortium of 25 Western Washington Tribes, including Jamestown. WWIETP is fully funded by the Federal Workforce Investment Act, which was enacted to provide training, education and employment for adults, displaced workers and youth. WWIETP's directive is to provide work experience and education assistance necessary for self-sufficiency exclusively to qualifying American Indians and Alaska Natives. The program allows us the opportunity to serve Tribal Descendants and individuals with other Tribal affiliations residing in our service area.

### **NATIONAL BUDGET PRIORITIES**

#### **Exempt Tribes from Sequestration and Rescissions and Restore 2013 Sequestration Cuts -**

**Budgetary** reductions undermine Indian Treaty Rights and Federal obligations. The Federal trust obligation must be honored and vital programs and services for Tribes must be sustained despite the budget deficit. We urge Congress to exempt Tribes from any further reductions imposed by the Budget Control Act and to restore funding cuts incurred in by the 2013 sequestration and rescissions.

#### **Department of Health & Human Services**

##### **1. Special Diabetes Program for Indians – provide \$200 million a year for five years**

Recently extended until October 1, 2017 at the current rate of \$150 million, the Special Diabetes Program for Indians (SDPI) has been flat-line since 2004. The SDPI program has proven effective in combatting diabetes and enhancing care and education in AI/AN communities. As a result, the

program has successfully reduced costly health complications and the incidence of the disease itself.

**2. Full Funding for Streamlined Implementation of the Patient Protection and Affordable Care Act and the Indian Health Care Improvement Act – provide Full Funding** - The Indian Health Care Improvement Act (IHCIA) permanently authorizes health care to improve health care conditions for approximately two million American Indians / Alaska Natives. However, there are more than twenty-five unfunded provisions in the IHCIA. Implementation of the new authorities and the improvement of the health status of Native health hinges upon the provision of full funding.

**3. Restore Funding for Child Welfare Services (Social Security Act Title IV-B, Subpart 1) – provide \$280 million** - Tribal Child Welfare Program Funds are administered at the Tribal community and allows for flexibility enabling Tribes to provide culturally appropriate services to families for in-home services, support services for Native children in foster care, case management, training and professional development. Tribes share in the state allocation but the median Tribal grant is a little over \$13,000 a year, preventing many Tribes from participating in the program due to the cost of implementation. A program increase is necessary to ensure that all Tribes are able to address the child welfare needs within their communities.

**4. Substance Abuse and Mental Health Services Administration – American Indian and Alaska Natives Suicide Prevention – restore funding to \$2.97 million** - Alcohol and drug use is at epidemic levels as many individuals use it as a means to self-medicate and the impacts extend beyond the individual to our Tribal families and community. This program provides funding to support technical assistance and training to Tribes on how to leverage existing



resources to implement prevention plans to address bullying, violence and suicide in Tribal communities.

**5. Tribal Prevention Grants Program – provide \$45 million over FY 2015 request** -The inaugural funding for the program was in FY 2014 for \$5 million which, startling as it may be, was the same level appropriated for FY 2015. Only 20 Tribes received \$.02 million annually for five years to help them develop the comprehensive plan. We request \$45 million over the 2015 enacted amount to expand these activities throughout Tribal communities where behavioral health problems have a powerful negative impact on our citizens and economy

**Department of Education**

**1. Title I, Part A, Local Education Agency Grants provide \$25 million** - Approximately 600,000 American Indian / Alaska Native youth attend the public school system in the United States. Title I of the Elementary and Secondary Education Act (ESEA) provides essential financial assistance to schools with high levels of low-income families to ensure that all children meet the required educational standards established by the state. Inflation and sequestration have impacted the ability of states to administer this critical program and a drastic increase in funding is essential.

**2. Impact Aid Title VIII funding provide \$2 billion** - Impact Aid provides essential funding to public schools serving American Indian / Alaska Native students. The program provides payments in lieu of taxes to public school districts for loss of property taxes that support their educational programs. In order to ensure that Native students have equal access to quality education, impact aid must be funded.

**Thank you on behalf of the Jamestown S’Klallam Tribe.** I respectfully request that these recommendations be included in the FY 2016 budget in order to honor the trust responsibility and support Tribal prosperity and well-being.

**Testimony of the American Academy of Pediatrics  
Concerning Fiscal Year 2016 Appropriations**

*Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies*

April 29, 2015

Submitted by: Sandra G. Hassink, MD, FAAP, President of the American Academy of Pediatrics

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The American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong federal investments in children's health in Fiscal Year 2016 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term federal spending decisions. AAP supports robust funding of the Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Health Resources and Services Administration (HRSA), and the Administration for Children and Families (ACF), which fund important programs that ensure the health and safety of children. Specifically, we would like to highlight our support for investment of \$21.116 million in the Emergency Medical Services for Children program at HRSA, \$131.78 million for the CDC's National Center for Birth Defects and Developmental Disabilities, \$219 million for CDC's Global Immunization program, including \$169 million for CDC Polio Eradication and \$50 million for the CDC Measles program, and \$650 million for CDC's Section 317 program.

To improve the state of the child in this country, the AAP is focused on meeting the most basic needs of children: access to health care and education, sound nutrition, nurturing relationships and safe environments. As pediatricians, we not only diagnose and treat our

patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital federal programs. As such, we urge you to pass strong policies that invest in children in the earliest days of life and we implore you to take meaningful strides to address chronic poverty and its impacts on the health and well-being of American families.

**Emergency Medical Services for Children (HRSA)**

**FY 2016 Request: \$21.116 million; FY 2015 Level: \$20.1 million.**

Established by Congress in 1984 and last reauthorized in 2014, the Emergency Medical Services for Children (EMSC) Program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure that state of the art emergency medical care for the ill and injured child or adolescent pediatric services are well integrated into an EMS system backed by optimal resources, and the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

Gaps in providing quality care to children in emergencies continue to persist throughout the country. The EMSC program helps to address these gaps by promoting the quality of care provided in the pre-hospital and hospital setting, reducing pediatric mortalities due to serious injury, and supporting rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

**National Center for Birth Defects and Developmental Disabilities (CDC)**

**FY 2016 Request: \$131.78 million; FY 2015 Level: \$131.78 million.**

The National Center for Birth Defects and Developmental Disabilities is a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential

for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. The center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities. The center also conducts important research on fetal alcohol syndrome, infant health, autism, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD has proven to be an asset to children and their families and supports extramural research in every State.

### **Global Immunizations (CDC)**

**FY 2016 Request: \$219 million; FY 2015 Level: \$208.6 million.**

Vaccines are one of the most cost-effective and successful public health solutions available. They save the lives of approximately 2.5 million children each year. Recent studies estimate that scaling up the use of existing vaccines in 72 of the world's poorest countries could save 6.4 million lives and avert \$6.2 billion in treatment costs and \$145 billion in productivity losses by 2020. Since 1988 a coordinated global immunization campaign has reduced the number of polio cases globally by more than 99 percent, saving more than 10 million children from paralysis and bringing the disease close to eradication. Expanded immunization has also reduced the global mortality attributed to measles, one of the top five diseases killing children, by 74 percent between 2000 and 2010.

The AAP calls on Congress to fully support CDC's Center for Global Immunization, which provides technical assistance and surveillance support to country ministries of health, with a focus on eradicating polio, reducing measles deaths, and strengthening routine vaccine delivery. The Center for Global Immunization enhances global capacity for vaccine safety

monitoring and post-marketing surveillance, builds global immunization research and development capacity, and strengthens countries' capacity for vaccine decision-making.

### **Section 317 Program (CDC)**

**FY 2016 Request: \$650 million; FY 2015 Level: \$610 million.**

Section 317 is a discretionary federal grant program that provides vaccines to underinsured children and adolescents who are not eligible for the Vaccines for Children program, as well as for uninsured and underinsured adults. Throughout its history, Section 317 has played an important role in ensuring that these individuals are receiving vaccinations that prevent life-threatening diseases. As we have seen in the recent measles outbreak in California, vaccines are a crucial part of our public health infrastructure.

Though the Affordable Care Act now requires that insurers provide first dollar coverage of vaccines, Section 317 still plays a valuable role in other areas, particularly in vaccine infrastructure and in handling outbreaks. Section 317 has helped public health departments around the country to optimize their billing processes so that they can be reimbursed for insured patients to whom they administer vaccines. Additionally, Section 317 plays an important role in containing outbreaks. If a large outbreak were to occur, Section 317 funds could be used to vaccinate individuals in the affected area, and could supplement the efforts of the CDC to effectively combat the outbreak.

In his FY 2016 Budget, the President proposed that Section 317 funding be cut by \$50 million. The AAP urges Congress not to cut these funds from the program. Though the Affordable Care Act is now a part of our healthcare system, many aspects of it are still being rolled out, and it is important that we are not hasty in cutting a program that so clearly works and rely on another one that is still in its relative infancy.

### **Healthier children, healthier future**

On behalf of the 75 million American children and their families that we serve and treat, the nation's pediatricians hope that Congress will respond to mounting evidence that child health has life-long impacts and prioritize children while determining FY 2016 Federal spending levels. Federal support for children's health programs, such as early brain and child development, parenting and health education, and preventive health services, will yield high returns for the American economy. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the nation's long-term fiscal health as well.

We fully recognize the nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Rather, focusing on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace.

The AAP is focused on meeting the most basic needs of children: access to health care and education, sound nutrition, nurturing relationships, and safe environments. There are many ways Congress can help meet children's needs and protect their health and well-being. Adequate funding for children's health programs is one of them. The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our nation's children in FY 2016 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at 202-347-8600 or [pjohnson@aap.org](mailto:pjohnson@aap.org). Thank you for your consideration.



**Written Testimony of Akua F. Kouyate-Tate, Senior Director, Education**

**Wolf Trap Foundation for the Performing Arts**

**Public Hearing**

**House Committee on Appropriations Subcommittee on**

**Labor, Health and Human Services, Education and Related Agencies**

**Washington, DC**

**April 29, 2015**

On behalf of Wolf Trap Foundation for the Performing Arts, I am pleased to submit this written testimony in support of the US Department of Education Arts in Education (AIE) grant program and to request that you appropriate \$30 million in FY16 and retain AIE as a distinct grant competition in the appropriation. As a recipient of the AIE Model Development and Dissemination grant and a leader in the field of early childhood arts integration educational programs, I want to share with you the importance of AIE and the positive affect it has had advancing STEM learning through the arts in early childhood.

Across the nation, Wolf Trap uses the performing arts to provide innovative strategies for early childhood education, professional development for teachers, and parent training. Wolf Trap Foundation is a nonprofit organization that produces and presents a full range of performance and education programs in Northern Virginia as well as nationally reaching more than 400,000 people of all ages in 30 states.



We applaud the Subcommittee for working in a bipartisan manner to find ways to ensure fiscally responsible budgets and to promote innovation and creativity necessary for the 21<sup>st</sup> Century workforce. The Arts in Education program promotes these attributes, ensures that rigorous evaluation is conducted of model arts integration strategies, and requires that the model program and research results be shared nationally, so that they can be duplicated or adapted by school districts and organizations across the country.

Wolf Trap Institute for Early Learning Through the Arts provides effective arts-integrated direct services to children while supporting systemic change through innovative, relevant professional development. The performing arts are effective in teaching children of multiple learning styles, supporting all developmental domains, and providing the foundation for all future learning.

Wolf Trap has been at the forefront of educational thinking and practice since 1981 when Head Start requested Wolf Trap's assistance in developing an early childhood program integrating the arts in instruction that aligns and supports curricula and education standards. Wolf Trap Institute coaches teachers in using active, arts-integrated learning techniques in the classroom, while simultaneously providing quality performing arts experiences for children birth to five. Since the beginning teachers, children and their parents throughout the nation have benefited from Wolf Trap Institute's model of arts-integrated active learning as a means to enhance young children's school readiness. In 2013-14 school year alone, Wolf Trap Institute provided





educational services focused on ensuring young children's success and readiness to 55,688 people in 30 states, including 41,575 students; 8,741 educators; and 5,372 parents.

Independent research of the Wolf Trap model, research from the arts education and early childhood fields, and Wolf Trap Institute's over 30 years of experience, confirm that the infusion of performing arts strategies in instruction aids significantly in developing children's skills across curriculum content and supports education standards including Head Start Child Development and Early Learning Framework and states' early childhood curricular standards. The performing arts provides powerful teaching tools that enhance all areas of development including language and literacy, social/emotional growth, health and wellness, STEM skills (Science, Technology, Engineering and Math) as well as 21<sup>st</sup> Century skills of critical thinking and problem solving, communication, collaboration, and creativity.

In 2010 the US Department of Education AIE program awarded Wolf Trap a four-year grant to research and disseminate our Early Childhood STEM Learning Through the Arts (Early STEM/Arts) program which focused specifically on math. The study was conducted by the American Institutes for Research, one of the most esteemed third-party social science research and evaluation firms. The study was independent, randomized, controlled, and spanned four years – in short, it met the gold standard for research design. This research indicated that Wolf Trap's early childhood programs are measurably impacting student achievement: that children participating in Wolf Trap programs show significant advances in math achievement as



compared to their peers. Additionally, this third-party evaluation confirmed that Wolf Trap’s approach demonstrated notably six features of effective professional development for teachers. In explaining the results the researchers stated that “the effects found in this study are non-trivial, notable, and larger than the effects found in many impact studies of education interventions.”

As the AIE program requires, Wolf Trap disseminated the Early STEM/Arts model program and research results nationally in 30 states and replicated it through 17 Wolf Trap Affiliate Programs across the country. Wolf Trap is continuing to inform the broader community of Early STEM/Arts through webinars, online resources, and presentations at professional development conferences in the early childhood and arts education field. Wolf Trap also launched an online website <http://education.wolftrap.org> that includes public, free access to examples of Wolf Trap lesson plans, videos and research, along with other professional learning materials on arts integrated math learning in early childhood. Wolf Trap’s success illustrates the value of the AIE in efficiently promoting innovation and creativity in education throughout the country.

In conclusion, Wolf Trap Foundation is honored to share our experience as a recipient of AIE funds and as a national leader in early childhood learning through the arts. We urge the Subcommittee to include AIE funding in its FY16 appropriations legislation.

# Deinstitutionalization of People with Intellectual and Developmental Disabilities in the United States: Was This Good Social Policy?

*James W. Conroy, Ph.D., President, Center for Outcome Analysis*

610.246.5961, [www.eoutcome.org](http://www.eoutcome.org)

April, 2015

The scientific evidence on the outcomes of deinstitutionalization of Americans with intellectual & developmental disabilities is clear and compelling. The outcomes are consistently found to be positive, both in the sense of improved qualities of life, including health and safety, and in terms of cost-effectiveness.<sup>1</sup>

This paper provides a point by point summary of the major aspects of the evidence. All of the full body of knowledge and citations are readily available for thorough review. The evidence begins with children, but extends naturally to adults with disabilities.

## **1) Large group setting are not good for children, or for adults with disabilities.**

Although large scale congregate care settings (institutions) may have been designed with good intentions, beginning in the U.S. in about 1850, they were soon found to develop inevitably into pernicious patterns. The original importer of the model, and America's greatest expert in the disability field in the 1800s, was Samuel Gridley Howe. Less than two decades after he advocated the model of large residential settings, he said:

[It is] best ... bringing up the child among ordinary children, and subjecting him to ordinary social and family influences ... People run counter to this principle for the sake of economy, and of some other good end, which they suppose cannot be had in any other way, as when they congregate the insane in hospitals, vicious children in reformatories, criminals in prisons, paupers in almshouses, orphans in asylums, blind children and mute children in boarding schools. ... all such institutions are unnatural, undesirable, and very liable to abuse. (Quotes in Trent, 2012).

America moved away from large group settings for children – orphanages – during the twentieth century, for good reason. With the benefit of scientific hindsight, we can now fully explain the inevitable and irreparable harm done to children in institutional or orphanage settings. Just four studies can summarize the entire body of knowledge about orphanage harm.

First, the work of Spitz beginning in 1945 revealed a phenomenon of harm to children that he called "Hospitalism." In those days most orphanages were operated medically, as

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<sup>1</sup> The only exception to this pattern was an unreplicated series of mathematical mortality analyses in institution and community by Kastner and colleagues, financed by institutional advocates, that have since been thoroughly discredited by the detection of incorrect counting of deaths in institution and community (Lakin, 1999).

“hospitals.” He studied large groups of children in orphanages, and found permanent damage to be inflicted. The number of months in a large group setting was directly related to how much damage was done. Spitz also found a critical period for emotional and social attachment development, which, if missed by living in a large group setting, could never be remedied.

Next, the work of Harlow with primates, familiar to every introductory psychology student as “Harlow’s Monkeys” (beginning with Harlow, 1965), revealed irreparable emotional damage from lack of individual attention. This supported the Spitz demonstration of Hospitalism. But Harlow went further and explored the biological basis for the damage in brain structures. The lack of a warm mother or any individually loving figure was shown to be devastating.

Thus the dangers of social deprivation were known from the 1960s onward, but it took an extremely well-designed series of scientific studies in Romania in the 21<sup>st</sup> century to show how inevitable such deprivation was in orphanage settings. Nelson et al. (2007) conducted a series of controlled experiments in the devastated nation of Romania, assigning some children to family homes and others to orphanages, at random. These were highly controversial experiments, to be sure, but the importance of the knowledge for many millions of future children was very great. The Nelson group at Harvard and other leading academic centers showed that no matter the funding or staffing or physical accoutrements of the orphanage, the same harm was done to young children, and it was irreversible. No amount of variations in management or organization was found to remedy the lack of individual love and attention experienced by children in large group settings.

Finally, Tottenham et al. (2010) discovered exactly where in the brain this irreparable damage takes place. They found it with the most advanced brain scan techniques, never before available to scientists. An area of the brain that is intimately involved in social-emotional behavior and control of aggression, the amygdala, was shown to be the most heavily affected by early life in large group settings. No amount of training or stimulation could repair this underdeveloped area, once the critical periods in early life were missed.

In summary, we now know with great certainty that large group settings – institutions and orphanages – do terrible and permanent damage to the developing infant and child. It is now clear and worldwide policy that no child should grow up in a large group setting. This is

expressly stated in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities:

Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

The Convention's use of the word "community" was intentional – it excludes large scale isolated and segregated settings.

What follows from this clear knowledge is that adults are not likely to "benefit" from institutional settings. The research in the U.S. and other countries has been unequivocal on this topic, with the finding that adults, particularly adults with intellectual & developmental disabilities, are far better off when they leave institutions.

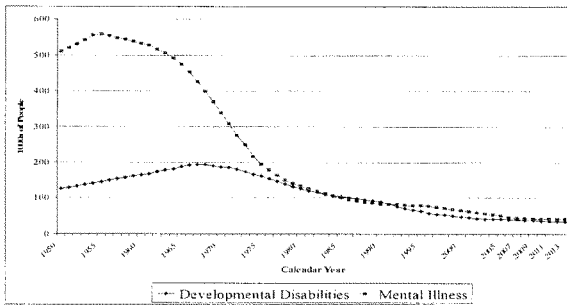
**2) Research Shows Multiple Benefits of Community Placement:** Thirty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The literature is remarkably consistent in this area. Dozens of rigorous studies have been done in the U.S. and in other nations. I personally have been involved in some of these studies, beginning with the first large one – the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). I began my work in this area with a strong hypothesis that the outcomes of moving people out of Pennhurst would be unfavorable (Conroy, 1977).

The most recent summaries of the literature on this topic are by the Institute for Family Advocacy and Leadership Development (2007) and Lemay (2009). They document the unanimity of the evidence from scientific studies. Older reviews, such as Larson & Lakin (1989) showed the same consistent pattern.

Today, again with the benefit of scientific hindsight, we know with great confidence that people with intellectual & developmental disabilities who have moved from institution to community are better off in nearly every way we know how to measure.

**3) Deinstitutionalization in Developmental Disabilities Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field:** The deinstitutionalization of nearly 100,000 American citizens with developmental disabilities has been highly successful. This is a very different experience from the nation's failure to support people with mental illness who

have left state psychiatric hospitals. The graph shows the history of deinstitutionalization in the two fields, and they are quite different in the numbers of people involved, and when they began.



The negative experience of deinstitutionalization in the mental illness domain was documented early (Bassuk & Gerson, 1978). It continues today with American prisons being called “America’s new mental hospitals” in the New York Times (Harcourt, 2007). This difference — success in deinstitutionalization for people with intellectual & developmental disabilities, versus dismal results in deinstitutionalization for people with mental illness, has been the source of tremendous misunderstanding in the media, the public, and in government.

**4) Family Attitudes Change Dramatically Toward Favoring Community Options:** Families (parents, siblings, other relatives, guardians, best friends) of people living in institutions overwhelmingly supported the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people moved to the community, the families’ attitudes changed dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement became ardent supporters of community living once it had been experienced (McCalment, 2012). The Pennhurst Longitudinal Study was the first to show this phenomenon (Conroy & Bradley, 1985). Later work in Oklahoma revealed even more dramatic changes in family opinions from opposition to support of community living (Conroy, 1999). The same changes occurred among thousands of California families (Conroy & Seiders, 1998). A review article of all rigorous studies of family reactions to deinstitutionalization revealed this as a consistent finding across the scientific literature (Larson & Lakin, 1991).

**5) The Theory of the “Must Stay” Group is Not Supported:** There are four classic reasons given for keeping people in large segregated settings: severe retardation, challenging behavior,

medical fragility, and advanced age. These reasons have been convincingly discredited by carefully controlled studies of community placement, by evidence from total closures during the past 35 years, by the fact that 14 states are now entirely free of public institutions as a living option.

Another argument that must be raised only to be dismissed is that closing institutions will cost jobs. Even if that were true, and it was not true in the first large scale closure at Pennhurst, it cannot be seriously maintained that treating human beings with less than the best quality supports we have cannot be justified by the employment of others.

**6) Community Support Systems are More Cost Effective than Institutional Systems:** All studies published thus far are consistent. Community service models are less costly than institutional models. It must be recognized, however, that this is because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not. The most comprehensive review of the comparative cost issue is given in Stancliffe & Lakin (2005).

**7) Community Living is Not Without Problems and Requires Protections:** The clear and compelling scientific evidence on the benefits of community living should not be construed to mean that every single individual will be better off in every way, and at all times, in a community setting. Problems must be expected, and to the extent possible, they must be anticipated and prevented through carefully considered protective orders, monitoring, and quality assurance feedback systems, just as in the Pennhurst decision and other subsequent orders and settlements.

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Disability Rights Florida House Subcommittee Testimony

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**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email on April 29, 2015:** [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)

As the Executive Director of Disability Rights Florida, the Protection and Advocacy (P&A) agency for Florida, I submit this testimony into the record of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies. My testimony includes information about the FY 14 outcomes produced by the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program in Florida, including outcomes related to community integration, access to services, elimination of abuse and neglect, and protection of education, employment, housing, and health care rights.

Through the PADD program, Disability Rights Florida served 475 individual clients, conducted 14 trainings for 440 people, and provided informational and referral services to an additional 750 people during FY 14. In addition, thousands of people, including recipients of developmental disabilities waiver services, special education students, people with developmental disabilities under guardianship, and residents of large facilities, as well as other groups of people with intellectual disabilities or developmental disabilities, were positively impacted by various legal and systemic advocacy efforts. For the record of this subcommittee, I submit the following specific examples:

- **A.D.** was a youth with intellectual disabilities who we assisted with a community integration concern. A.D. was denied attendance to a public summer camp program covered by Title II of the Americans with Disabilities Act. Disability Rights Florida found that the camp's reasons for denying A.D. were based on misinterpretations of outdated information about A.D.'s behavior. The camp did not understand the progress A.D. had made as a result of nearly two

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years of intensive behavioral therapy and the ongoing involvement of professionals who were committed to assisting camp staff. A.D.'s therapists reported increased positive behavior and also outlined how A.D. would benefit from the camp program. Additionally the therapists were planning to assist the summer camp program and help prevent and address any negative behaviors that might arise. Based on Disability Rights Florida's investigation and advocacy on A.D.'s behalf, the camp reversed its decision and A.D. had a very successful 2014 summer experience.

- **M. A.**, an individual with multiple disabilities including a digestive disorder, heart and other circulatory conditions, intellectual disability, muscular/skeletal impairment, and pervasive developmental delays, was assisted with care coordination and rights issues. The family's electric bill had risen to nearly \$8000 because of the equipment M.A. needed for support. Disability Rights Florida assisted the parent in writing a letter to request special assistance from the electric company. The electric company responded appropriately by adjusting the past due amount and providing special rates going forward. Our advocacy also resulted in the Children's Medical Services case worker assigned to M.A. becoming a more active partner in the support of M.A.'s needs and the parent now has better means to communicate with the case worker about any issues that arise in the future.

- **J.J.** was a minor with autism and intellectual disabilities residing at a residential treatment center for children and adolescents. J.J.'s parents contacted Disability Rights Florida with concerns about neglect and weight loss. J.J.'s feeding plan called for a liquid diet, but the facility was providing fewer total daily calories than J.J. had been previously receiving and there was weight loss as a result. We requested that the nutritionist review the plan and as a result, J.J. began being fed more often and the facility also began offering soft snacks several times a day. J.J. also needed 1:1 staff due to elopement and self-harm issues. In addition to successfully addressing that staffing need, we also secured changes to J.J.'s programming to better support the development of J.J.'s safety and independence skills.

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- **P.L.** was a teenager who died at a private facility receiving HCBS waiver dollars for individuals with developmental disabilities. Disability Rights Florida learned about P.L.'s death as a result of the Casey Family Foundation report following its review of Florida's child protection system. After learning that P.L. had died while being restrained, our staff investigated and found substandard evaluation and treatment by medical personnel, poor communication and documentation between direct care staff and nurses, a dangerous reliance on the use of restrictive behavioral intervention techniques and ineffective staff training all contributed to the death. As a result of our investigation, we shared recommendations with facility administration and the Agency for Persons with Disabilities (APD) about reforms we determined were necessary to improve the facility's system of care and prevent further tragedies. APD placed a moratorium on individuals being admitted to the facility and both APD and our organization monitored implementation of the recommendations. The facility worked to correct deficiencies by improving documentation, systems of care and communication, as well as revising restraint procedures. We were very concerned that critical evidence of events leading to the death had been compromised. The video evidence that should have recorded most of the child's last night was destroyed so we requested the video monitoring be extended in these circumstances and should include an audio track. The facility is co-operating and is holding quarterly meetings with stakeholders to report on its progress.

- Disability Rights Florida used the **Individuals with Disabilities Education Act State Complaint** provisions to raise and attempt to resolve systemic special education concerns at the state, district, and school levels. Outcomes in 3 such complaints removed barriers to inclusion and the provision of free and appropriate public education as follows:

- **DRF v. Duval County School District:** We filed for a complaint with the Florida Department of Education in April 2014 based on reports that students in Duval County were not receiving appropriate direct instructional supports per their Individual Education Plans (IEPs). The school district was listing services on

students IEPs that required direct staff support (co-teaching, support facilitation, adult assistance, etc.) but the staff were not providing the services because they were also being assigned to other tasks (i.e. attending meetings, assessments of other students and other miscellaneous duties). The Department of Education found that Duval County was indeed not providing direct instruction as stated on the student's IEP and required several corrective actions including compensatory services for the impacted students.

- **DRF v. Broward County School District:** We filed a Complaint with the Department of Education in June 2014 alleging that Broward County School District violated its Child Find obligations with regard to timely evaluation and timely provision of parental consent forms to parents following the district's determination that a student may be a student with a disability. We also alleged that Broward County was using the Response to Intervention process to delay the evaluation of students suspected of having a disability and therefore denying the students a free and appropriate public education. Mediation was offered and within a month, the following actions were agreed to:
  - District would send a memo to Principals explaining the requirements for identification/evaluations of students suspected of having a disability
  - District would produce proof of retraining of school staff
  - District would create a web-based training for classroom teachers on newly adopted MTSS/RtI framework
  - District would create an updated web-based training on Procedural Safeguards 2013 for parents and post to the Parent Resources section of website
  - District would create web-based trainings on Parent Requested Evaluations for parents and school-based professionals

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- District would add many other specific links to the Parent tab of their website
  - School would provide face to face training for parents without online access
  - Most importantly, the District would require that schools create a plan to address the needs of the nearly 3000 students in Tier 3 of RTI at the time of the filing of the complaint.
- **DRF v. Coconut Creek Elementary School:** We filed a state complaint against Coconut Creek Elementary School in July 2014. The complaint was based on reports that students who required Resource Room and/or services from the Resource teacher as outlined on their Individualized Education Plans were not receiving them in violation of their right to FAPE. In September after investigation, the Department of Education found that Broward County School District had violated the FAPE requirement by not implementing the IEPs appropriately. The Department of Education found that specially designed instruction was not being provided as required to 13 students at the school. The District's corrective action included identifying students in need of compensatory education and developing a plan for compensatory services. The Department of Education identified other issues and required corrective actions to address them as well.
- And finally, to support the advocacy of others, we provided trainings addressing topics such as Person Centered Planning and Supported Decision Making, Alternatives to Guardianship, Guardianship and International Law, Service Animal Rights and Responsibilities, Differentiating Perspectives: Parent and School Board Attorneys, School to Work Transition, Self-Determination for Transitioning Students, Restraint and Seclusion, Keeping the Behaviorally Challenged Student in School, Service Dogs in School, Dispute Resolution, and Assistive Technology.



**Testimony of the American Dental Education Association**  
**Submitted for the Record to the Subcommittee on**  
**Labor, Health and Human Services, Education, and Related Agencies**  
**Committee on Appropriations**  
**United States House of Representatives**

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The American Dental Education Association (ADEA) represents all 66 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. ADEA submits this testimony for the record and for your consideration as you begin prioritizing fiscal year 2016 appropriation requests.

ADEA urges you to protect the funding and fundamental structure of federal programs providing access to dental care to millions of Americans, educating the next generation of dental professionals and enabling globally recognized cutting-edge dental and craniofacial research.

ADEA's academic dental institutions educate future practitioners and researchers. As one of the major providers of dental care in some federal programs, they provide significant dental safety-net care through dental clinics where students and faculty deliver care to uninsured and underserved populations. The proven, inextricable link between good oral health and good systemic health makes the need to provide

access to oral health care critical. However, in order to provide these services, there must be adequate funding. Therefore, we ask the committee to help ADEA's member dental schools and programs continue to provide care to the entire population, including perhaps your constituents, by maintaining adequate funding for such programs. Specifically, we request that you maintain and protect funding for Title VII of the Public Health Service Act; National Institutes of Health (NIH); National Institute of Dental and Craniofacial Research (NIDCR); Dental Health Improvement Act; Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program; and Centers for Disease Control and Prevention (CDC), State-Based Oral Health Programs.

The above programs fund public health initiatives proven to prevent oral disease, fund research to eradicate dental disease, detect certain cancers and fund programs to develop an adequate dental workforce with advanced training to serve underserved populations including children, the elderly and those suffering from chronic immunocompromised conditions and life-threatening diseases. ADEA respectfully makes the following funding requests:

**I. \$35 million: Title VII, Section 748, Public Health Service Act**

The dental programs in Title VII, Section 748 of the Public Health Service Act, provide critical training in general, pediatric and public health dentistry and dental hygiene. Support for these programs will help ensure an adequate dental workforce. The funding supports predoctoral dental education and postdoctoral pediatric, general and public health dentistry residency training. The investment made by Title VII not only

educates dentists, dental therapists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. There are currently more than 200 open, budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty. ADEA is increasingly concerned that with projected restrained funding, the dental research community will not be able to grow and that the pipeline of new researchers will not meet future need.

Title VII Diversity and Student Aid programs play a critical role in diversifying the health professions student body and, thereby, the health care workforce. For the last several years, these programs have not received adequate funding to sustain the progress necessary to meet the challenges of an increasingly diverse U.S. population.

ADEA is most concerned that the Administration did not request any funds for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for dental professionals serving underserved and disadvantaged patients by providing a pipeline for individuals from these populations. This unique workforce program encourages young people from diverse and disadvantaged backgrounds to explore careers in health care generally and dentistry specifically. The president's budget request seeks to "rebrand" the HCOP program as the Health Workforce Diversity Program (HWDP). ADEA supports the goals of this proposed new program as long as the current funding follows the new program.



Another vital program targeted at enhancing high-quality, culturally competent care in community-based interprofessional clinical training settings is the Area Health Education Centers (AHEC) program. The infrastructure development grants and point of service maintenance and expansion grants ensure that patients from underserved populations receive quality care in a technologically current setting and that health professionals receive training in treating such diverse populations. ADEA strongly encourages the Committee to continue funding the critically important AHEC program.

**II. \$18 million: Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and Community-Based Dental Partnerships Program**

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. The Dental Reimbursement Program (DRP) is a cost-effective federal/institutional partnership providing partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Simultaneously, the program provides educational and training opportunities to dental residents, dental students and allied dental students. However, in FY 2013, DRP only reimbursed 26% of the dental schools' unreimbursed costs. The current reimbursement rate is unsustainable. Remember that good dental care is essential to good overall systemic care, thus, dental care is imperative to the health and well-being of people living with HIV/AIDS. Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive critical dental care.

**III. \$425 million: National Institute of Dental and Craniofacial Research (NIDCR)**

Dental research serves as the foundation of the profession of dentistry. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better dental health for millions of Americans and uncovered important links between oral and systemic health. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the nation's dental, and overall, health. Dental researchers are poised to make dramatic breakthroughs, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; and diagnosing systemic disease from saliva instead of blood samples (such as HIV and certain types of cancer). These breakthroughs, which continue America's role as a global scientific leader, require adequate funding.

**IV. \$20 million: Division of Oral Health, Centers for Disease Control and Prevention (CDC)**

The CDC Division of Oral Health expands the coverage of effective prevention programs. The Division increases the basic capacity of state oral health programs to accurately assess the needs of the state, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of dental disease affecting children and vulnerable populations. The current path of decreased funding will have a significant negative effect upon the overall health and preparedness of the nation's states and communities.

ADEA thanks you for your consideration of these funding requests and looks forward to working with you to ensure the continuation of congressional support for these critical programs.

Please use ADEA as a resource on any matter pertaining to academic dentistry under your purview.



Project Open Hand  
 meal with love

**Testimony Prepared by Simon Pitchford, Ph.D., co-Chief Executive Officer, Project Open Hand for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services**

**Wednesday, April 29, 2015**

We are pleased to submit this testimony to the Members of this Committee on the urgency of funding the Ryan White Program at \$2.45 billion for Fiscal Year 2016 (FY16) to better ensure that all people living with HIV receive treatment and are retained in care. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Open Hand is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 1.04 million medically tailored meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

**1.) Why Food and Nutrition Services (FNS) Matter for PLWHA**

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase

absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

## **2.) FNS as a Care Completion Service Unique to Ryan White**

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

### **3.) Access to FNS and the Triple Aim**

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

#### **Better Health Outcomes**

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>i</sup>. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections<sup>ii</sup> and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads<sup>iii</sup>
- More ER visits<sup>iv</sup> & increased morbidity and mortality<sup>v</sup>
- More missed primary care appointments & reduced use of antiretroviral therapy<sup>vi</sup>.

#### **Lower Healthcare Costs**

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare

costs for PLWHA fell 80% (more than \$30,000) for first three months after receiving FNS<sup>vii</sup>. If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution<sup>viii</sup>. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

### **Improved Patient Satisfaction**

Studies show nutrition counseling improves quality of life<sup>ix</sup>. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

### **4.) FNS and the National HIV/AIDS Strategy (NHAS)**

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time<sup>x</sup>, thus, FNS is key to prevention<sup>xi</sup>.
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines<sup>xii</sup>.
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities<sup>xiii</sup>.

### **Conclusion**

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the FY 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



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Renee Shakir

Nursing Home Transition Program Manager

I work with individuals with a disability that currently reside in the nursing home and needs housing. The population that I serve has limited income which makes them ineligible for housing. The Nursing Home Transition Program Manager at disABILITY LINK builds business relationships with public and private housing managers to advocate for housing for individuals with a disability so they could live in the community. Without the support of disABILITY LINK, many of the individuals with a disability that reside in the nursing home would not be able to live in the community, work, feel like apart of society and be able to pay taxes.



NATIONAL OFFICE  
 Advocacy and Access Department  
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**Arthritis Foundation Written Testimony**

**House Appropriations Committee**

**Subcommittee on Labor, Health and Human Services, and Education and  
 Related Agencies**

**Fiscal Year 2016**

**Contact: Sandie Preiss, Vice President of Advocacy and Access,  
[spress@arthritis.org](mailto:spress@arthritis.org), 202-887-2910**

On behalf of the 52 million adults and 300,000 children living with doctor-diagnosed arthritis in the U.S., the Arthritis Foundation thanks Chairman Cole and Ranking Member DeLauro for the opportunity to provide written testimony to the Appropriation Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for Fiscal Year 2016. **We respectfully request a minimum of \$32 billion for the National Institutes of Health (NIH) and \$13 million for the Centers for Disease Control and Prevention (CDC) Arthritis Program for FY 2016.**

Arthritis affects 1 in 5 Americans and is the leading cause of disability in the U.S., according to CDC. It limits the daily activities of nearly 23 million Americans and causes work limitations for 40% of the people with the disease. This translates to \$156 billion a year in direct and indirect costs from two forms of arthritis alone – osteoarthritis (OA) and rheumatoid arthritis (RA). There is no cure for arthritis, and for some forms of arthritis like OA, there is no effective pharmaceutical treatment. Research is critical to build towards a cure, to develop better treatments with fewer severe side effects, and to identify biomarkers and therapies for types of

arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

### **National Institutes of Health (NIH)**

As previously stated, there is no cure for arthritis, and for some forms of the disease, no effective pharmaceutical treatments. Even for auto-immune forms of the disease like RA, biologic medications – which have revolutionized treatment by halting the progress of disease in many patients – have severe side effects. There is also no “gold standard” diagnostic for many forms of arthritis like RA and juvenile arthritis, and therefore it can take a long time to diagnose these diseases. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics and better treatments, so that people have access to treatments early in their disease, ensuring a higher quality of life and better health outcomes.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. There are a number of initiatives supported by NIAMS to better understand arthritis. The Osteoarthritis Initiative is a public-private, multi-center, longitudinal study of knee OA that was launched in 2002 with the goal of identifying biomarkers for OA as potential surrogate endpoints for onset and progression. The recently launched Accelerating Medicines Partnership is a public-private partnership that includes RA/lupus as one of three disease topics with the goal of accelerating drug development.

Research currently supported by NIAMS is addressing major questions necessary to unlocking the unknowns of arthritis, such as: how gene-environment interactions can help determine the relationship between RA and environmental and genetic factors that trigger onset; which biological pathways are affected in people with RA and how drug development can target those pathways to expand the pool of drugs available to people with RA; and how existing successful anti-rheumatic drugs may be used for other arthritis-related diseases.

Most recently, researchers have found the gene that confirms the existence of psoriatic arthritis. This is a breakthrough that has the potential to lead to targeted therapies for psoriatic arthritis, and even treatments that can prevent its onset. These research breakthroughs can have an enormous impact on the quality of life for people with arthritis, in addition to generating a strong return on investment in reduced health care costs and better quality of life for patients.

A strong overall NIH funding level is critical to maintaining the investment in research on arthritis in all its forms. **Therefore, we urge you to fund NIH at a minimum of \$32 billion in FY16 to keep pace with the growing research needs in the arthritis community.**

#### **Centers for Disease Control and Prevention (CDC) Arthritis Program**

The CDC Arthritis Program is the only federal program dedicated solely to arthritis. It provides grants to 12 states to support public health programs, provide education services, perform public health research, and support data collection. Its goal is to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like Enhance Fitness help keep older adults active, and have shown a 35% improvement in physical function, resulting in

fewer hospitalizations and lower health costs compared to non-participants. Further, 1 in 4 veterans has doctor-diagnosed arthritis, and these evidence-based exercise programs are recommended by the CDC to help our veterans reduce the impact of arthritis on their lives.

Kentucky is one of the 12 CDC-funded states, and with this federal support, the Kentucky Arthritis Program enhanced its partnership with the Kentucky Department of Aging and Independent Living to increase the delivery and sustainability of evidence-based disease management programs. The impact to-date is a 58% increase in the number of participants in the program from 2013 to 2014, translating to over 5,000 Kentuckians having access to program services. The Kentucky program has improved the quality of life for people with arthritis by creating new social outlets, and reducing pain and medication use through the exercise and education programs.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Because of this support, we know that 1 in 5 Americans has doctor-diagnosed arthritis, including 27% of people in Oklahoma and 24% of people in Connecticut, and 415,000 of those people in Oklahoma and 267,000 of those people in Connecticut are limited by their arthritis. Without the Arthritis Program, the robust level of data collection we have now would not exist. As you know, this data is critical for determining where to direct public health programs and how to set research priorities. For example, because of the data on the high number of people with arthritis who also have at least one other chronic disease like heart disease (24%) or diabetes (16%), we know that research on co-morbidities and coordinated chronic disease programs are important to reducing the overall impact of chronic

disease on people with arthritis.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully underfunded compared to the investment in other chronic diseases. Despite the low funding level of \$13 million in FY14, the program was slated for elimination in FY15. While the program was preserved, the funding was cut by 25%, bringing the FY15 total to \$9.5 million. The Arthritis Program staff must now determine how to support the same level of programs in 12 states with 25% fewer resources.

In 2013 for the first time, data showed that arthritis affects at least 20% of the population in every state. **All 50 states need funding from the Arthritis Program.** While this is a long-term goal, a critical first step is to restore the program to its full funding level so it can continue its current level of operations in the 12 states it supports. **Therefore, we urge you to restore the \$3.5 million to the CDC Arthritis Program, bringing the total program level back to \$13 million in FY16.**

We thank the Subcommittee for its commitment to public health. As you write the FY16 Labor-HHS-Education appropriations bill, **we urge you to fund NIH at a minimum of \$32 billion and to restore the CDC Arthritis Program to its full funding level of \$13 million in order to continue the investment in improving the lives of people with arthritis.** Please contact Sandie Preiss, the Arthritis Foundation VP of Advocacy and Access at 202 887 2910, [spreiss@arthritis.org](mailto:spreiss@arthritis.org) or the Arthritis Foundation Director of Health Policy and Federal Affairs Anna Hyde at [ahyde@arthritis.org](mailto:ahyde@arthritis.org) or 202-887-2917 with any questions.

**HOUSE COMMITTEE ON APPROPRIATIONS  
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION AND RELATED AGENCIES**

**TESTIMONY BY  
THE HUMANE SOCIETY OF THE UNITED STATES AND  
HUMANE SOCIETY LEGISLATIVE FUND  
ON THE FY 2016 BUDGET – NATIONAL INSTITUTES OF HEALTH  
APRIL 29, 2015**

*Contact: Kate Wall, The Humane Society of the United States, Federal Affairs  
2100 L Street NW, Washington, DC 20037  
202-955-3672/kwall@humanesociety.org*

*Sara Amundson, Humane Society Legislative Fund  
2100 L Street, NW, Suite 310, Washington, DC 20037  
202-676-2314/samundson@hslf.org*

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2016.

**RETIREMENT OF FEDERALLY OWNED CHIMPANZEES**

The HSUS and HSLF request that the committee ask for information and updates from NIH on their progress towards retiring all but 50 of the government-owned chimpanzees from laboratories—a plan they announced in June of 2013 which will not only result in a better life for the chimpanzees but will also save taxpayer dollars. Further, we request that the committee push for the prioritization for retirement of the 20 government-owned chimpanzees at the Texas Biomedical Research Institute because of major concerns about the welfare of animals at the facility and the health and age of the chimpanzees housed there.

Further basis of our request can be found below.

**Slow Progress on Chimpanzee Retirement**

In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimpanzees in NIH funded studies and not revitalize breeding of chimpanzees for research. These decisions



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resulted from an Institute of Medicine study in 2011 which found that chimpanzees are not necessary for the vast majority of research.

Not including the 110 government-owned chimpanzees at the New Iberia Research Center who were already about halfway through the process of being transferred to sanctuary, approximately 360 government-owned chimpanzees remained in laboratories at the time of NIH's announcement—310 of whom should be slated for retirement to sanctuary per NIH's plan. However, according to a recent CNN news report, out of the 360 chimpanzees, only 6 have been retired to sanctuary thus far, and more than 20 have died in laboratories. Further, an NIH spokesperson noted the selection of the 50 chimpanzees could take "several years" and that it would happen before retiring more chimpanzees. It is unclear why it would take so long to choose the 50. Based on their timeline for protocol review, NIH should now have a good idea of what research (if any) this group of chimpanzees may be used for. It has been nearly two years since the plan was announced and we and other members of the public are becoming increasingly frustrated with the slow pace of progress on this issue.

Sanctuaries are more humane and less expensive than laboratories

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs (see chart below). It is estimated that transferring those government-owned chimpanzees slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayers approximately \$2.2 million per year in care and maintenance costs.

At Chimp Haven, the National Chimpanzee Sanctuary, chimpanzees are the sole focus of the facility and its staff. There, chimpanzees receive the very best care possible, including access to expansive outdoor habitats, large social groups and regular and varying enrichment.

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Conversely, the main mission of biomedical research laboratories is to conduct research and these facilities are often bound by limitations (i.e., mission, space, and research considerations). Thus, the laboratory environment suits the needs of researchers and not the animals. Laboratories simply cannot offer the high quality of care that sanctuaries do.

**Current Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:**

Government Owned Chimpanzees in Research Facilities and Research Reserve Facilities			
Facility	# of chimpanzees	NIH cost, \$M/year	NIH cost, \$/chimpanzee/day
Keeling Center for Comparative Medicine and Research	156 <sup>1</sup>	2.56 <sup>2</sup>	44.97
Texas Biomedical Research Institute, U42 grant <sup>3</sup>	20 <sup>1</sup>	0.56 <sup>2</sup>	76.5
Alamogordo Primate Facility	154 <sup>1</sup>	4.09 <sup>1</sup>	60.36
<b>Totals</b>	<b>330</b>	<b>7.21</b>	<b>Average: 60.61</b>

Government Owned Chimpanzees in Sanctuary			
Facility	# of chimpanzees	NIH cost, \$M/year	NIH cost, \$/animal/day,
Chimp Haven	191 <sup>1</sup>	2.73 <sup>1</sup>	39.23

Government Owned Chimpanzees at Texas Biomedical Research Institute

There are currently 20 government owned chimpanzees at the Texas Biomedical Research Institute (TBRI). Most of these chimpanzees are elderly and have been infected with HIV, hepatitis C and/or hepatitis B and have been through countless invasive experimental procedures throughout their lives. These chimpanzees are clear candidates for retirement. Further, the US Department of Agriculture has cited TBRI multiple times over the past few years for violations of the Animal Welfare Act that have resulted in death of five nonhuman primates, among other serious issues. The facility was cited for AWA violations as recently as February 2015 and the USDA is currently investigating the facility.

<sup>1</sup> Based on information available on the NIH website regarding chimpanzee maintenance costs

<sup>2</sup> Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT)

<sup>3</sup> In addition to this grant, NIH also supports an additional 85 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not eligible for government funded retirement to sanctuary under the Chimpanzee Health Improvement Maintenance and Protection Act.

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Given the age, history and health of these chimpanzees, the serious animal welfare concerns and the high cost of maintaining the chimpanzees at TBRI, we ask the committee to urge NIH to prioritize these 20 chimpanzees for retirement to Chimp Haven.

We respectfully request the following committee report language, which is supported by The HSUS and HSLF:

*The committee is aware of and commends NIH's stated commitment to retiring the vast majority of government owned chimpanzees to sanctuary, as it will provide these chimpanzees with the high quality care they deserve and save taxpayer dollars. However, the committee notes that the progress of chimpanzee retirement since the 2013 decision has been slow. It has been reported that since the announcement only 6 of the 360 government owned chimpanzees in labs have been retired and more than 20 have died in labs. The committee asks that NIH provide an update on the status of the process for determining whether chimpanzees will be retired or kept in the reserve colony of 50 and provide the committee with a list of government-owned chimpanzees that includes name, ID number, location, date of birth, sex and any designations made thus far regarding retirement or reserve colony for each individual. Please also provide any updates to the committee on whether or how many research projects using chimpanzees have been approved by NIH and/or the NIH's Chimpanzee Research Use Panel thus far. Finally, the committee has concerns about the welfare of the 20 government-owned chimpanzees at the Texas Biomedical Research Institute. This lab has been cited for numerous violations of the Animal Welfare Act in recent years. Further, many of these chimpanzees are elderly and infected with hepatitis and/or HIV. Given these issues and the high cost to maintain them in this laboratory, the committee requests that NIH prioritize their retirement to sanctuary.*

We appreciate the opportunity to share our views on the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2016. We hope the Committee will be able to accommodate this request. Thank you for your consideration.

**THE NATIONAL CENTER FOR ADVANCING TRANSLATIONAL SCIENCES**

The National Center for Advancing Translational Sciences (NCATS) is one of 27 Institutes and Centers (ICs) at the National Institutes of Health (NIH). Established to transform and accelerate the translational research process, NCATS is all about getting more treatments to more patients more quickly. The Center complements other NIH ICs, the private sector and the nonprofit

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community; rather than concentrating on specific diseases, NCATS focuses on what is common among them.

**Translation** is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public — from diagnostics and therapeutics to medical procedures and behavioral changes.

**Translational science** is the field of investigation focused on understanding the scientific and operational principles underlying each step of the translational process.

#### Bridging the Gap

Several thousand genetic diseases affect humans, of which only about 500 have any treatment. A novel drug, device or other intervention can take about 14 years and cost \$2 billion or more to develop, and about 95 percent never make it past clinical trials. Even when a new drug or other intervention is developed and shown to be effective in clinical trials, many years may pass before all patients who could benefit from it are identified and treated.

Here are some areas the animal protection community and industry have supported:

- Tissue Chip for Drug Screening (Tissue Chip) initiative. This partnership with the Defense Advanced Research Projects Agency and the Food and Drug Administration (FDA) is designed to develop 3-D human tissue chips that model the structure and function of human organs, such as the lung, liver and heart, and then combine these chips into an integrated system that can mimic complex functions of the human body.
- Toxicology in the 21st Century (Tox21) initiative. Tox21 is a collaborative effort among NIH — including NCATS and the National Toxicology Program at the National Institute of Environmental Health Sciences — the Environmental Protection Agency and the FDA. Through Tox21, researchers are testing 10,000 drugs and environmental chemicals for their potential to affect molecules and cells in ways that can cause health problems. The compounds undergo testing in NCATS' high-speed robotic screening system.

**We respectfully request the Subcommittee fund NCATS at the President's budget level which is \$27,000,000 over the Fiscal Year 2015 request.**

**Person Submitting Testimony: Gloria Prevost, Executive Director Protection and Advocacy for People with Disabilities, Inc. 3710 Landmark Drive Columbia, SC 29204 803 217 6713**

**Testimony Prepared For:** House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

**Regarding:** U.S. Department of Health and Human Services (HHS) Agencies

**Submitted by email: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)** (Subject Line: FY 2016 written testimony for the record)

I write today to submit testimony for the record demonstrating the work of Protection and Advocacy for People with Disabilities, Inc. (P&A), the Protection and Advocacy organization for South Carolina on community integration and ensuring access to services for people with intellectual and developmental disabilities.

Since its enactment in 1975, P&A agencies through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program have been working to ensure that individuals with intellectual and developmental disabilities are free from abuse and neglect (both in institutional settings and the community) and that their rights and desires are respected and considered as decisions are made concerning education, employment, housing, and health care.

Services for individuals with development disabilities:

In 2014, P&A served 135 individual clients, held eleven trainings, attended by 476 individuals, and provided informational and referral services to an additional 307 people.

In addition to these activities, 92,316 people were impacted by the activities undertaken by P&A on behalf of groups of clients. These activities included monitoring of conditions in facilities and systemic litigation.

As an example of the work done by P&A concerning community integration and accessing services for people with intellectual and developmental disabilities, see below two examples of our work on these topics in 2014.

A parent of a 15 year old student with an intellectual disability contacted P&A after visiting her child's special education classroom during an open-house session. She had learned that her son would spend most of his day in a segregated classroom located in the back of the campus, down a dark, hot hallway---the only section of the school that had been upgraded. The mother was told by the principal and other school officials by phone and writing that students with disabilities had always been in that section and liked being together (segregated?). The mother worked with P&A to advocate for an equal classroom for her son and other children with disabilities in that district. The intervention was successful: the district moved the classroom into an integrated space. Recently I met both the parent and her son and he is doing well in school.

A 21 year old with Pervasive Developmental Disorder and other physical and mental disabilities had been a client of multiple state agencies. He aged out of children's services with no transition to adult services, was inappropriately placed in an assisted living setting. The operator of that facility left him at the emergency department of a local hospital. He spent the next eight months living in the emergency department while providing agencies

argued over who was responsible. P&A advocated for an appropriate placement. His transition has continued to be difficult due to the trauma of life in an ER.

Thank you for this opportunity to submit this testimony. My contact information is [prevost@pandasc.org](mailto:prevost@pandasc.org) or 803 2176713 if there questions I may answer.



American Society for Nutrition  
*Excellence in Nutrition Research and Practice*

April 28, 2015

Testimony from Simin Nikbin Meydani, D.V.M., Ph.D.

2014-2015 President, American Society for Nutrition

Director, Jean Mayer USDA Human Nutrition Research Center on Aging at Tufts  
University

The Honorable Tom Cole

Chairman

Appropriations Subcommittee on Labor,

Health and Human Services, Education  
and Related Agencies

U.S. House of Representatives

Washington, DC 20515

The Honorable Rosa L. DeLauro

Ranking Member

Appropriations Subcommittee on Labor,

Health and Human Services, Education  
and Related Agencies

U.S. House of Representatives

Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

Thank you for the opportunity to provide testimony regarding Fiscal Year (FY) 2016 appropriations. **The American Society for Nutrition (ASN) respectfully requests \$31.3 billion dollars for the National Institutes of Health (NIH) and \$172 million dollars for the Centers for Disease Control and Prevention/ National Center for Health Statistics (CDC/ NCHS), consistent with the President's budget requests, in**

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**Fiscal Year 2016.** ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 5,000 members working throughout academia, clinical practice, government, and industry.

### **National Institutes of Health (NIH)**

The NIH is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally-funded basic and clinical nutrition research. Although nutrition and obesity research makes up less than eight percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent, and the proportion of older adults with chronic disabilities has dropped by one-third. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. A decade of flat-funding, followed by sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately

to progress. Increasing the NIH budget to \$31.3 billion dollars would help to restore the funding that was lost to sequestration and support additional competing research project grants. **ASN recommends \$31.3 billion dollars for NIH in Fiscal Year 2016,** consistent with the President's budget request and asks that Congress direct the use of some of these funds for both intra- and extramural human nutrition research. NIH needs sustainable and predictable budget growth in order to fulfill the full potential of biomedical research, including nutrition research, and to improve the health of all Americans.

**Centers for Disease Control and Prevention National Center for Health Statistics (CDC NCHS)**

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the nation's principal health statistics agency. **ASN recommends a Fiscal Year 2016 funding level of \$172 million dollars for NCHS,** consistent with the President's budget request, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure. This request would provide \$160 million in budget authority and \$12 million in mandatory Prevention and Public Health Fund.

The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our nation's children.

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/ Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess ‘nutrients of concern’ such as calcium, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in the area of health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

To continue support for the agency and its important mission, **ASN recommends an FY 2016 funding level of \$172 million for NCHS.** Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding FY 2016 appropriations for the National Institutes of Health and the CDC/ National Center for Health Statistics. Please contact John E. Courtney, Ph.D., Executive Officer, if ASN may provide further

assistance. He can be reached at 9650 Rockville Pike, Bethesda, Maryland 20814; 301.634.7078; or [jcourtney@nutrition.org](mailto:jcourtney@nutrition.org).

Sincerely,

Simin Nikbin Meydani, D.V.M., Ph.D.

2014-2015 President, American Society for Nutrition

April 29, 2015

My name is Valerie Heard and my son and I are both visually impaired, living on a fixed income. Due to the limited funds I receive from SSI, there is not much that I can do financially, but thanks to help of disABILITY LINK's Voucher Travel Assistance Program, it has allowed me to become more mobile. I have increased my independence and I have also been able to keep scheduled doctor's appointments. I now have the peace of mind that I have funds designated specifically for transportation.

I have also attended disABILITY LINK's Peer Support Training where I participated in 3-day training. The training I received has empowered me to share my life experiences with other individuals with disabilities. I am very grateful for the services I have received from disABILITY LINK.

-Valerie Heard

Written Testimony of

Patrick J. Raglow

Executive Director, Catholic Charities of the Archdiocese of Oklahoma City, Inc.



to the House Appropriations Subcommittee on Labor, Health & Human Services, and Education

The Honorable Tom Cole, Chairman

Dear Representative Cole and the members of the House Appropriations Subcommittee on Labor, Health & Human Services, and Education,

Thank you for your service to your constituents and all Americans in your work to pursue public policy that strengthens communities and expands opportunity across this great nation. I am Patrick Raglow, Executive Director of Catholic Charities of the Archdiocese of Oklahoma City, a 501(c)(3) human services organization rooted in our Roman Catholic faith.

In 2014, we served more than 16,000 Oklahomans across 46 counties of Central and Western Oklahoma through 16 different social service programs. Of those 16,000 Oklahomans, the youngest client is not yet born in our Crisis Pregnancy Services, and our oldest client is 94 in sponsored Senior Housing. Last year, 76 percent of the clients we served earned less than \$15,000 per year.

Yet these statistics, as powerful as they are, represents only one experience of the more than 160 agencies across the Catholic Charities USA network, each one serving their local community with a variety of service programs tailored to meet specific needs and realities. Some of these agencies receive extensive support from federal, state and local government, while others, such as my agency, Catholic Charities of the Archdiocese of Oklahoma City, rely significantly more on local support from their faith and service communities.

On behalf of those we are privileged to serve and Archbishop Paul S. Coakley of the Roman Catholic Archdiocese of Oklahoma City, I want to thank you for granting me this opportunity to discuss these different approaches across our network taken in the work we do alongside or as part of U.S. government programs to strengthen families, respond to those affected by natural disaster, care for children and seniors, and, in general, serve those in need.

This committee has difficult choices to make regarding how to allocate admittedly large sums of hard-earned taxpayer dollars across an even greater sweep of pressing needs. You are challenged with competing constituencies, well-informed and well-intentioned or not, and a sound-bite and caricature-ridden coverage of the choices you face and the decisions you make.

In this climate, your opportunity to constructively engage with others of good will on how to best steward taxpayer resources, while ensuring that policy and funding decisions first consider those who are without and which acknowledges their dignity, is limited. I believe that we can and must move past rhetoric where one side is characterized as "all they want to do is throw money out the window" while the other is characterized as "wanting to throw Grandma out the window." Neither caricature is accurate nor serves the common good. The serious challenges facing us warrant a healthier discourse.

I hope to suggest a different lexicon for the discussion. Instead of whether we should, or should not, spend limited resources on those in need, perhaps we can look at how and why we should choose to do so. For the socially conscious, and I count myself among you, it is not



merely a matter of allocating money. If money were the only ingredient necessary to address need in our society, need would have long since been addressed. For the fiscal conservatives, and I count myself among you, federal resources are an absolutely critical component to addressing societal need. These resources are both critically necessary, and yet, regardless of amount, they will always be insufficient. Societal needs cannot be served without necessary dollars, and dollars alone, of whatever magnitude, will never be enough. As a society, we have an undeniable obligation to serve those poor in our midst, but that obligation calls us to do so with today's resources and not those of future generations. We should not trade one injustice for another.

Although a laudable goal, I do not believe or proclaim that we can truly "end poverty." For if we ended poverty today, it would begin anew tomorrow, through loss of a job, a house fire, a tornado, cancer, death or divorce, or any of a thousand life-altering circumstances that often impoverish those affected. So I don't try to end poverty. What I do believe is that we can, and must, mitigate the worst effects of poverty on individuals subject to it, and shorten the time individuals experience poverty, and this, this we do every day.

This is where the network of local not-for-profit service agencies, such as local Catholic Charities agencies in communities all across this country, comes in. Each Catholic Charities agency is itself a good steward of its resources, whether from the federal, state or local governments, or from local foundations, business communities, or individual supporters. Each Catholic Charities, like many other reputable, similar local agencies, knows its community, its needs and composition, its network of service providers and its neighborhoods. Some Catholic Charities operate with budgets over \$200 million, others with under \$200,000. My own agency, Catholic Charities of the Archdiocese of Oklahoma City, operates normally with a budget of approximately \$5 million.

Across the network, some Catholic Charities agencies rely heavily on federal or state funding, Low-Income Housing Tax Credit-funded facilities, and many more. Others eschew such funding, preferring to use community resources given them to complement those services funded by the government. In each case, however, the local Catholic Charities positions itself to secure funding in the manner best suited to the sensibilities and needs of its community.

Furthermore – and this is the heart of the matter – each Catholic Charities seeks to engage those it serves *in a relationship* to best address the conditions which brought the client to us, and not merely transfer resources to cover immediate needs. By "in a relationship," I mean case management, and ideally intensive case management, to join with our clients on a path to self-sufficiency, toward ends which draw from the client's own resources and talents, aspirations and objectives.

Case management is not about adding to their circle of friends, nor is it about proselytizing. We serve others not because they are Catholic but because we are; in other words, clients do not have to attend services to receive services. Recognizing the dignity and gifts of

their humanity, Catholic Charities agencies seek to serve others in ways that elevate each client's ownership of his or her situation and its path forward, providing tools and skills while connecting the client with available resources. Catholic Charities agencies do this in full collaboration with other community providers such as the Salvation Army, Regional Food Bank, City Rescue Mission, and many others. There is plenty of need present in our communities; service providers need not compete with one another. Case management seeks to use all available resources as a means to address immediate unmet needs, while also using those resources as a bridge to relationship, for it is in relationship that we connect the individual to society and society to the individual.

Relationship through case management stretches federal and other resources by connecting explicitly with the client, drawing on his or her insight and talent, and challenging the client to employ his or her own gifts on a path to self-sufficiency with dignity. Case management addresses informational poverty that often leads to financial poverty. It connects individuals with agencies, programs, examples and tools to first chart and then follow a path to self-sufficiency. Properly executed, case management prevents duplication of service and coordinates effective service approaches from multiple agencies to strengthen each client's progress toward self-sufficiency. At its best, case management is client-centered, client-empowering, and ultimately, client-releasing.

Allow me a few examples that illustrate the game-changing power of case management. Shortly after the Great Recession, I was associated with a food pantry program that served 125 clients a day, Monday through Friday, in a very hard-hit community. It was a fabulous program in many respects: clients were treated well and with dignity, they could select their preferred protein, vegetable, grain, dairy, and even donated desserts, all from a clean, store-like environment. They were allowed to select food their family would actually eat, not simply accept whatever happened to be in the bag that week. It was, in many respects, an excellent and well-run program that ensured those at risk of going hungry could reliably access food. Yet I noticed that two and a half years later, too many of our clients were still returning monthly to participate in accessing our food pantry. We had done some things incredibly well, but we had, in retrospect, failed to address the conditions that had brought that family to us, and help them to succeed such that our food pantry supplies were no longer needed.

At the other end, I witnessed the success of that agency's welfare-to-work program, which coupled the resources available through multiple sources with intensive case management. Staff empowered clients through efforts including budgeting, skill and resource development, child care, and housing support, all time-limited and structured so as to have the client increasingly responsible for their own needs, and ultimately transitioning to self-sufficiency. The program boasted an 86% success rate – incredible.

In like fashion, one of my Oklahoma colleagues, Mr. Rodney Bivens of Oklahoma's Regional Food Bank, has launched an initiative to partner with Catholic Charities, the Salvation

Army, and other service providers to use food as the resource to other resources, or as I've characterized earlier, food as the bridge to a relationship. There is no better food bank operation in the states in my opinion, but Rodney understands that in addition to assisting individuals, families, and, most importantly, children with food, we have to address the conditions that bring them to the Food Bank. To paraphrase Rodney, he wants to "feed the line while partnering with agencies like mine to "shorten the line."

These first two items are related: First, the need for intensive case management, and second, the critical role the federal government plays and must play in meeting needs of those on the margins of our society. While dollars are not the only solution, they are nonetheless necessary for that solution. Individuals rarely have a relationship with the federal government – but they do have relationships with their neighbors, with church families, school groups and organizations, and the like. Local agencies do create and sustain working relationships with those they serve, leveraging government resources to accomplish what resources alone cannot and could not ever build. I submit that pairing the resources with relationship is essential to improving lives, and therefore to meeting the intent of the allocation in the first place.

One final note – I've mentioned above that agencies like Catholic Charities often work closely with federal agencies and resources in the services through which we engage our communities. We are pleased to work in concert with our government to address those least among us. Like all Catholic Charities agencies across the country, Catholic Charities of the Archdiocese of Oklahoma City provides help and hope to all in the Catholic tradition of service. Catholic Charities recognizes the God-given dignity of all persons, whether client, staff, or contributor. In the scope of our more than 16 service programs across 46 counties of Central and Western Oklahoma, we serve all persons in accordance with that dignity, regardless of race, religion, creed, or gender. Recognizing the dignity of all persons is the cornerstone of our service.

We serve because our agency is Catholic, not because our clients are Catholic. Our clients are not required to affirm Catholic values. Catholic Charities does not require our clients to accept Catholic teaching in order to receive services. While Catholic Charities recognizes, respects and complies with applicable civil law, we expect equal respect from our federal government, our state and local communities, and those we serve, that we not be asked to affirm views, take actions, or hold positions which are at odds with Catholic values. Please consider this simple request as you create or consider legislation to allocate resources to address need in our communities.

Your work as our representatives at the federal level is a great responsibility, as you weigh how to steward federal resources in ways that will strengthen society, advance the common good, and create opportunity for all. In your discussions around appropriations, I ask that if you err, err first on the side of those in need, and when doing so, to favor those programs

and approaches that offer strengthening relationship opportunities through case management or similar along with the resources your decisions will make available for that purpose.

Thank you for your consideration of these matters, and for your service to all Americans.

Respectfully,

Patrick J. Raglow

Executive Director

Catholic Charities of the Archdiocese of Oklahoma City, Inc.

**Testimony of the Friends of NIDDK Regarding Fiscal Year (FY) 2016 Appropriations for the  
National Institute of Diabetes and Digestive and Kidney Diseases  
U.S. House Committee on Appropriations Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
Submitted by Jim Twaddell, Staff Consultant, Friends of NIDDK**

For Fiscal Year 2016, the Friends of NIDDK encourages the Labor, Health and Human Services, Education and Related Agencies Subcommittee to increase funding for research programs and activities that focus on preventing and treating acute and chronic disease and other illnesses and eliminating health disparities. In particular, **the Friends of NIDDK request a funding level of \$2.066 billion in FY 2016 for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).** This funding level is an increase of approximately 8% over FY 2015 and a 6.2% increase over the President's FY 2016 budget request. NIDDK is charged with an extensive research portfolio that covers diabetes, chronic kidney disease, liver disease, digestive diseases, urologic diseases, and endocrine diseases such as hypothyroidism. Given the large burden that these and other diseases confronted by NIDDK place on the U.S. health care system, economy, and quality of life years, the Friends of NIDDK believes that increased support for efforts that will reduce this burden is warranted.

**About the Friends of NIDDK**

The Friends of NIDDK is a coalition of professional societies and patient advocacy groups with a vested interest in promoting and sustaining the vital research activities of NIDDK. The Friends of NIDDK was established in 2013 with the vision of uniting organizations to speak with one voice about the important research being conducted by the Institute, and to ensure that these critical dollars continue to increase in future years. The Friends of NIDDK work to educate

Members of Congress about the scientific advances made through the Institute's ongoing research and the critical importance of increased federal funding for future scientific initiatives. In just the short time since its inception, over 40 national and local organizations have joined the Friends of NIDDK to rally their support of the Institute's activities.

### **About NIDDK**

NIDDK is the fifth largest institute at the National Institutes of Health and coordinates research on many of the most serious diseases affecting public health. The mission of NIDDK is to "conduct and support medical research and research training and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people's health and quality of life."

The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country, and supports scientists who conduct basic, translational, and clinical research across a broad spectrum of research topics and serious chronic diseases and conditions. In addition, NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs, including the National Diabetes Education Program, the National Kidney Disease Education Program and the Weight-control Information Network, to bring science-based information to patients and their families, health care professionals, and the public.

### **U.S. Disease Burden**

The diseases that are included within NIDDK's research portfolio are some of the most common, yet costly, diseases impacting Americans. Chronic diseases are the nation's leading causes of morbidity and mortality and account for 75 cents of every dollar spent on health care in the U.S. For example, an estimated 29.1 million people in the United States have diabetes. The estimated price tag for the diabetes epidemic in 2012 was \$322 billion<sup>1</sup>. About 26 million American adults have chronic kidney disease (CKD) and millions of others are at increased risk. Urologic diseases affect people of all ages, result in significant health care expenditures, and may lead to substantial disability and impaired quality of life. Patients with cystic fibrosis, an inherited disease that primarily affects the lungs and digestive system, continue to face much lower life expectancy compared to healthy adults, despite dramatic advances in treatment. These diseases represent only a portion of the NIDDK research portfolio, but nonetheless underscore the need for continued investment.

### **NIDDK Successes**

The researchers at NIDDK are collaborating and using innovative technology to discover cross-cutting solutions that will ultimately reduce health care costs and improve quality of life for millions of Americans. NIDDK releases an annual report to illustrate the Institute's scientific advances, and incorporates personal stories of individuals that participate in NIDDK-sponsored clinical research. Recent innovations from the 2015 NIDDK annual report include:

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<sup>1</sup> The Economic Burden of Elevated Blood Glucose Levels in 2012: Diagnosed and Undiagnosed Diabetes, Gestational Diabetes Mellitus, and Prediabetes. Diabetes Care December 2014.

- Highly encouraging results from studies testing how well artificial pancreas technologies help people with type 1 diabetes improve their blood glucose (sugar) control in “real-world” settings outside the clinic;
- Identification of host and microbial factors associated with inflammatory bowel disease that could pave the way to new treatment approaches;
- Discovery that a widely used, costly bladder test was not necessary before surgical treatment of urinary incontinence, paving the way for significant cost savings without compromising patient care;
- A new understanding of why a cystic fibrosis treatment strategy is not working as expected, providing important insights in the quest to improve therapy for people with the most common mutation causing this disease; and
- Success in reversing sickle cell disease with a new, less aggressive blood stem-cell transplant regimen that could be an option for treating older or sicker adults with the disease.

### **The Need for Increased FY 2016 Funding**

Many scientific discoveries that have occurred over the past century can be attributed to the National Institutes of Health. Studies funded by NIDDK continue to contribute to pioneering efforts in many areas such as artificial pancreas technology, liver transplantation, and conducting the first major comparative effectiveness trial for the treatment of type 2 diabetes in young people. Other NIDDK studies have identified a genetic link to a rare intestinal cancer, and a gene that hastens kidney disease progression in African-Americans. These crucial findings will lead to the development of proactive approaches in treatment, diagnosis and



prevention. **The Friends of NIDDK strongly encourage the Subcommittee to support a robust investment at the Institute in order to build on these accomplishments that will advance science and pave the way for medical breakthroughs.**

### **Conclusion**

Thank you for this opportunity to present our views to the Subcommittee. We look forward to working with you to prevent chronic illness, improve the quality of lives, and reduce health care costs. Should you have any questions or require additional resources regarding NIDDK activities, please contact the Friends of NIDDK's Washington representative, Jim Twaddell, at [Jim.Twaddell@dbr.com](mailto:Jim.Twaddell@dbr.com) or (202) 230-5130.

House Committee on Appropriations Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies  
Testimony for the Record

by Mary Dimmock

April 29, 2015

My name is Mary Dimmock and I am submitting this testimony on behalf of my son and the nearly one million people in the United States who suffer from Myalgic Encephalomyelitis, or ME. The Centers for Disease Control (CDC) and the National Institutes of Health Office of Research and Women's Health are the primary two agencies that are tasked with addressing the federal response to ME.

ME is a serious, chronic disease that causes debilitating neurological, immunological and energy production dysfunction affecting an estimated one million Americans. Approximately 250,000 people are bedridden, housebound, or wheelchair-dependent, and up to 600,000 people are bedridden on their worst days. Americans with ME are more functionally impaired than those with congestive heart failure, multiple sclerosis, and end-stage renal disease. Recovery is rare and the limited information available suggests that patients may die up to 25 years prematurely from cancer, cardiovascular disease, or suicide. The economic impact is \$18-24 billion annually in lost productivity and direct medical costs.

Five years ago my son came down with ME. His experience with the medical system has been starkly different than those suffering from almost every other chronic illness. Doctors have told my son he is just depressed; was on the "wrong life path;" and that he

just “wants” to get onto disability, as though that is preferable to the vibrant life he lost. Two doctors insisted that he do aerobic exercise, while refusing to review the results of a gold-standard cardiopulmonary exercise test that recommended against such exercise. And worse, even as supportive as my son’s family and friends are, many have not understood the seriousness of the disease and have suggested that perhaps he just has a form of narcolepsy, needs electroshock therapy, should take up meditation, or maybe just needs to eat better. No disease-modifying drugs have been approved, and few drugs are capable of lightening the impact of the range of symptoms from which patients suffer. Few doctors even believe that ME is real and organic, much less understand how to treat it.

And yet, in spite of HHS involvement for the last thirty years, federal health policy toward this disease has failed to produce a single meaningful outcome for patients. Worse, their actions have turned patients and this disease into pariahs. As discussed in a recent report by the Institute of Medicine and a separate report published by NIH’s Office of Disease Prevention, there are no approved treatments and little symptomatic relief. Many doctors believe the disease is psychological or question whether it is real. Medical care is inadequate and too often abusive and harmful. Patients are stigmatized and disbelieved, sometimes by their own families. As the IOM report noted, “remarkably little research has been conducted” into disease etiology, pathophysiology, treatments or natural history and what research has been done is confounded by conflicting evidence from sloppily conducted studies.

These failures are the direct result of HHS policies and actions that include promotion of overly broad definitions, an excessive focus on psychological issues, flawed or non-existent research and epidemiological strategies, lack of defined milestones of progress, institutional barriers resulting from ME being orphaned outside of the NIH institutes, academic centers and medical societies that drive biomedical innovation and delivery, lack of coordination across HHS agencies and a resistance to working in open and honest collaboration with ME patients and disease experts, as evidenced by its refusal to accept input from fifty disease experts on how the disease should be defined. One objective measure of the failure is NIH's paltry research funding; at \$5M, ME funding ranks at 226 out of 234 diseases funded, is four percent of that spent on multiple sclerosis, a disease of similar morbidity but lower prevalence and only roughly 0.02 percent of the annual U.S. economic impact of ME. In fact, the total federal investment of about \$250 million over thirty years has produced nothing but confusion and disdain.

ME patients, too disabled and stigmatized to effectively advocate for themselves, are the ones that have paid the price. Vibrant lives suddenly crushed and replaced with a living hell. The stigma, the knowledge that no one is doing anything about ME and the lack of hope of ever getting better have too often led to suicide.

For thirty years, ME patients have tried to influence HHS to change its federal policy. ME experts have petitioned HHS requesting specific actions. HHS' own advisory committee (CFS Advisory Committee) has made repeated recommendations for action which have been largely ignored. Congress has provided guidance through its

appropriations process and has written letters to HHS with specific requests. Nothing has changed.

It is scientifically inexcusable and morally wrong that one million terribly disabled Americans have been mistreated and discarded in this way for three decades. This must stop. Congress should address the government's failure to confront the disease of ME by directing HHS to provide:

1. A fair share of funding for biomedical research commensurate with disease burden, roughly \$250 M a year, and aggressively applied to validate existing findings and study the known gaps in etiology, pathophysiology, diagnostics and treatments.
2. A disease definition such as the Canadian Consensus Criteria for both clinical care and research that accurately describes ME and clearly differentiates it from the disparate conditions encompassed by the outdated and inaccurate Fukuda and Empirical definitions and the "CFS" label.
3. Disease appropriate clinical guidance and medical education that teaches doctors about the true nature of ME and the best practices to diagnose and treat it.
4. A proactive medical education campaign to counter the false beliefs about ME that have been perpetuated for decades.
5. Regional centers of excellence that integrate clinical care and research to address the critical need for multi-disciplinary research and effective clinical care for patients.

6. A definitive, time-bound plan to reverse the organizational and institutional barriers resulting from ME being exiled outside of NIH's segmented Institute structure.
7. A plan to replenish the aging population of researchers and clinicians before it is too late for the next generation to learn from them.
8. A community-driven comprehensive, fully-funded, cross-agency strategy, with well defined objectives, timelines and measurable benchmarks and infused with the sense of urgency warranted by this thirty year old crisis. Such a plan must aggressively foster the academic and drug industry investment that will be required to make up for thirty years of governmental neglect.
9. Most importantly, HHS and its agencies must finally stop acting unilaterally and start engaging experts and patients openly, transparently and in true collaboration.

I appreciate the Subcommittee's consideration of these requests and am available to answer any question you may have. I have also provided a link to a detailed background reference that outlines the policy issues that have burdened this disease for thirty years.

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For more information, see: [http://bit.ly/The\\_Evaporation\\_of\\_ME](http://bit.ly/The_Evaporation_of_ME)

**Fiscal Year 2016 Testimony Submitted to the House Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Christopher V. Plowe, MD, MPH, FASTMH, President  
On behalf of the American Society of Tropical Medicine and Hygiene**

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The American Society of Tropical Medicine and Hygiene (ASTMH)—the principal professional membership organization representing, educating, and supporting scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals dedicated to the prevention and control of tropical diseases—appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee.

The challenges posed to global health by tropical diseases and the need for continued U.S. leadership and investment in research and development in this domain are perhaps best illustrated by the ongoing tragic Ebola outbreak in West Africa, the worst in history; to date over 25,000 people have been infected, with over 10,000 deaths and imported cases to the U.S. and Europe.<sup>1</sup> Although the most important barometer, the Ebola epidemic's toll cannot be measured in lives lost alone. Controlling the outbreak has necessitated billions of dollars of global investment (including \$5.4 billion in the FY 2015 Omnibus Appropriations Act). Furthermore, the economic and social toll has created worrisome national security issues in the already fragile West African sub-region.

Ultimately, the Ebola epidemic, along with the 2003 pandemic of SARS coronavirus and 2009 pandemic of influenza, vividly demonstrate the “interconnectivity” of our modern world. The U.S. cannot consider geographic distance from developing countries or “tropical diseases” as adequate protection against these infectious threats and their secondary economic, social, and political consequences. Rather a proactive strategy of robust U.S. investment in R&D is needed to ensure the knowledge and tools to confront the next infectious disease global health challenge.

The benefits gained from a strong U.S. investment in tropical diseases are humanitarian, diplomatic, and economic, and of direct relevance to U.S. health and security. With this in mind, we strongly advocate that the Subcommittee fully fund the NIH and CDC in the FY 2016 LHHS appropriations bill to ensure continued U.S. investment in global health and tropical medicine research and development, specifically:

**National Institutes of Health:**

- Research on infectious diseases transmitted by ticks, fleas, and mosquitoes that occur both within the borders of the U.S. and in tropical and subtropical regions abroad, including malaria and neglected tropical diseases (NTD) research and development efforts within the National Institute of Allergy and Infectious Diseases (NIAID);

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<sup>1</sup> CDC. 2014 Ebola Outbreak in West Africa - Case Counts. Available at: <http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html>

- Diarrheal disease research throughout the NIH; and
- Research capacity development in countries where populations are at heightened risk for malaria, NTDs, and diarrheal diseases through the Fogarty International Center (FIC).

#### The Centers for Disease Control and Prevention:

- The National Center for Emerging & Zoonotic Infectious Diseases, which protects the U.S. from new and emerging infections spread by vectors such as mosquitoes and ticks and other diseases that are normally maintained in animals but may infect humans, such as Ebola, SARS-coronavirus, chikungunya, and pandemic influenza viruses;
- The Center for Global Health, which includes CDC's work in malaria and NTDs; and
- The CDC's efforts to implement the Global Health Security Agenda.

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### Return on Investment of U.S.-Funded Research

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CDC and NIH play essential roles in research and development for tropical medicine and global health. Both agencies are at the forefront of the science that leads to new tools to combat malaria, epidemic viruses, NTDs and other infectious diseases. In addition to creating lifesaving new drugs and diagnostics to aid some of the poorest, most at-risk people in the world, in addition to the U.S. military and civilian travelers, this research provides jobs for American researchers and a leadership opportunity for the U.S. in the fight against global disease. Sixty-four cents of every US dollar invested in global health R&D goes directly to U.S. researchers.<sup>2</sup>

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### Tropical Disease

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**Malaria and Parasitic Disease:** First, I want to acknowledge the tremendous success we have seen as a result of U.S. funded malaria efforts. I want to thank the committee for its support. We have more to do and I can assure you, it is doable. Malaria remains a global emergency affecting mostly poor women and children, but also is a major threat to our military and other travelers to the tropics. It is an acute, and too often a fatal disease. Despite being treatable and preventable, malaria is one of the leading causes of death and disease worldwide. In 2014, 97 countries and territories had ongoing malaria transmission. According to the latest estimates, released in December 2014, there were about 198 million cases of malaria in 2012 and an estimated 584,000 deaths. Through collaborative efforts to fight malaria, malaria mortality rates have fallen by 47 percent globally since 2000. Still, approximately every minute, a child needlessly dies of malaria.<sup>3</sup>

**Neglected Tropical Diseases:** NTDs are a group of chronic parasitic diseases, which represent the most common infections of the world's poorest people. These treatable, preventable diseases reduce cognitive development, stunt growth, cause anemia in children and women of

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<sup>2</sup> Global Health Technologies Coalition and Policy Cures. *Saving lives and creating impact: Why investing in global health research works*. Available at: <http://www.ghtcoalition.org/files/Savinglivesandcreatingimpact.pdf>

<sup>3</sup> World Health Organization. *World Malaria Report 2014*. Available at: [http://www.who.int/malaria/publications/world\\_malaria\\_report\\_2014/cn/](http://www.who.int/malaria/publications/world_malaria_report_2014/cn/)



child-bearing age, and severely limit the future earning potential of men, women, and children across the developing world resulting in further economic drain in already strained countries. These infections are considered a primary reason why the “bottom billion”—the 1.4 billion poorest people living below the poverty line—cannot escape poverty.

**Diarrheal disease:** The child death toll due to diarrheal illnesses exceeds that of AIDS, tuberculosis, and malaria combined. In poor countries, diarrheal disease is second only to pneumonia as the cause of death among children under five years old. Each year diarrhea needlessly kills around 760,000 children under five<sup>4</sup> which, according to the most recent census estimates, is more than the population of Detroit, Michigan.<sup>5</sup>

The United States has a long history of leading the fight against tropical diseases that cause human suffering and pose financial burdens that negatively impact a country’s economic and political stability. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Additionally, some diseases such as dengue fever have been found in the U.S. Tropical diseases like West Nile virus and Chagas are no longer quarantined to the tropics and have taken root here. The U.S. is not immune. Viruses are but a plane ride away from any point in the world.

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### National Institutes of Health

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**National Institute of Allergy and Infectious Diseases:** A long-term investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria and NTDs. NIAID is the lead institute for malaria and NTD research. In the past year, NIAID reported significant progress in addressing malaria, including the recent development of low-cost diagnostic tests that can rapidly detect resistance of malaria to artemisinin, a first-line antimalarial drug.<sup>6</sup> Resistance to artemisinin is a growing danger and one that we must be aggressively addressing. NIAID also helped lead accelerated trials of an Ebola vaccine.

**ASTMH encourages the subcommittee to** increase funding for NIH to expand the agency’s investment in malaria, NTDs, tick-borne infections, and diarrheal disease research and coordinate with other agencies to maximize resources and ensure development of basic discoveries into usable solutions and specifically invest in NIAID to support its role at the forefront of these efforts to developing the next generation of drugs, vaccines, surveillance tools and other interventions.

**Fogarty International Center:** Biomedical research has provided major advances in the treatment and prevention of malaria, NTDs, and other infectious diseases. These benefits,

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<sup>4</sup> World Health Organization. *Diarrhoeal disease*. Available at: <http://www.who.int/mediacentre/factsheets/fs330/en/>

<sup>5</sup> U.S. Census Bureau. *Annual Estimates of the Resident Population for Incorporated Places of 50,000 or More*. Available at: <http://factfinder.census.gov/fares/tableservices/jsf/pages/productview.xhtml?src=blm&mk>

<sup>6</sup> National Institutes of Health. National Institute of Allergy and Infectious Diseases Fiscal Year 2016 Congressional Budget Justification. Available at: <https://www.niaid.nih.gov/about/Documents/FY2016CJ.pdf>

however, are often slow to reach the people who need them most. FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria, NTDs, and other infectious diseases. This maximizes the impact of U.S. investments and is critical to fighting malaria and other tropical diseases. In addition, the diplomatic goodwill gained through these partnerships between the U.S. and other countries, some of whom view the U.S. with some skepticism, is invaluable in building a renewed trust.

***ASTMH encourages the subcommittee to*** allocate sufficient resources to FIC to increase these efforts, particularly as they address malaria, NTDs, and diarrheal disease.

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### The Centers for Disease Control and Prevention

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**The Global Health Security Agenda:** In partnership with other government agencies, other nations, international organizations, and public and private stakeholders, CDC announced a Global Health Security Agenda in 2014 to “accelerate progress toward a world safe and secure from infectious disease threats and to promote global health security as an international security priority.” The Agenda focuses on preventing and reducing the likelihood of outbreaks, detecting threats early to save lives, and responding rapidly. The CDC’s Center for Global Health and National Center for Emerging & Zoonotic Infectious Diseases will play an important role in these efforts and must be supported through robust funding to carry out their duties.

**The Center for Global Health: Malaria and Parasitic Disease:** Malaria has been eliminated as an endemic threat in the United States for over fifty years, and the CDC remains on the cutting edge of global efforts to reduce the toll of this deadly disease. CDC efforts on malaria and parasitic disease fall into three broad categories: prevention, treatment, and monitoring/evaluation.

***ASTMH encourages the subcommittee to*** fund a comprehensive approach to effective and efficient malaria and parasitic disease elimination, including adequately funding the important contributions of CDC in malaria and parasitic disease at no less than \$24 million, a funding level that has not increased in many years.

**Neglected Topical Diseases:** CDC currently receives zero dollars directly for NTD work outside of parasitic diseases; however, this should be changed to allow for more comprehensive work to be done on NTDs at the agency. CDC has a long history of working on NTDs and has provided much of the science that underlies the global policies and programs in existence today.

***ASTMH encourages the subcommittee to*** provide direct funding to CDC to continue its work on NTDs, including but not limited to parasitic diseases and urges the CDC to continue monitoring, evaluating, and providing technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases.

**The National Center for Emerging & Zoonotic Infectious Diseases and its Vector Borne Disease Program** fund essential surveillance and monitoring activities that protect the U.S. from deadly infections before they reach our borders and address the problems of tick- and flea-transmitted infections such as Lyme disease and a dozen other infections, including Ebola, that can be life-threatening within the U.S. The world is becoming increasingly smaller and new pathogens are introduced quickly into new environments. We have previously seen this with SARS, avian influenza, and dengue fever in the United States.

Last year the CDC also issued warnings to clinicians across the U.S. to be on the lookout for patients showing symptoms of chikungunya, a debilitating mosquito-borne virus that is currently in the Caribbean and could soon break out across large parts of the Americas.

***ASTMH encourages the subcommittee to*** ensure that CDC maintains these vital activities by continuing robust funding for National Center for Emerging and Infectious Zoonotic Diseases.

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### Conclusion

Thank you for your attention to these important U.S. and global health matters. Tropical medicine/global health research saves lives and is a smart economic strategy for the U.S. We hope you will provide the requested FY 2016 resources to those programs identified above. ASTMH appreciates the opportunity to share its expertise, and we thank you for your consideration of these requests that will help improve the lives of Americans and the global poor.



# Testimony for the Record

## In support of FY 2016 funding for the Children's Hospitals Graduate Medical Education Program (CHGME)

Submitted to the Subcommittee on Labor, Health and Human  
Services, Education and Related Agencies, Senate Committee on  
Appropriations – April 29, 2015

The Children's Hospitals Graduate Medical Education (CHGME) program is administered by the Bureau of Health Professions in the Health Resources and Services Administration at the Department of Health and Human Services. The statement testimony focuses on the purpose of CHGME and its benefit to all children.

The testimony respectfully asks the subcommittee to appropriate \$300 million for CHGME in Fiscal Year 2016.

The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 institutions, the Association is the voice of children's hospitals nationally. As organizations dedicated to protecting and advancing the health of America's children, we thank the Subcommittee for its longstanding bipartisan support of the Children's Hospital Graduate Medical Education program (CHGME).

As a nation, our goal should be to ensure that no child lacks access to high quality medical care and a robust pediatric workforce is essential to achieving this goal. The CHGME program supports this goal by providing independent children's hospitals with funding to support the training of pediatric providers, much as Medicare supports training in adult teaching hospitals. CHGME benefits all children, supporting the training of doctors who go on to care for children living in every state — in cities, rural communities, suburbs and everywhere in between. **The Children's Hospitals Association urges the Subcommittee to protect children's health and fund CHGME at its authorized level of \$300 million for FY 2016.**

Congress created CHGME in 1999 with bipartisan support because it recognized that the absence of dedicated GME support for freestanding children's teaching hospitals created gaps in the training of pediatric providers, which potentially threatened access to care for children. Since then, the CHGME program has had a tremendous impact. Although the 56 hospitals that currently receive CHGME funding comprise only 1 percent of all hospitals, they train 49 percent of all pediatric residents—more than 6,000 annually—including 45 percent of general pediatricians and 51 percent of pediatric specialists.

CHGME has enabled children's hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialists being trained nationwide. Bipartisan legislation reauthorizing CHGME through FY 2018 was enacted in 2014, demonstrating the high level of ongoing support among lawmakers for the program.

However, while much has been achieved, much remains to be done, and our nation's commitment to children's health care still lags behind our investment in adults with respect to workforce training. Since 2000, the national population of children has grown 3 percent, increasing from 72.3 million to some 74.2 million today. At the same time, the health care needs of the child population are increasing. The number of children with complex medical conditions is growing at a faster rate than the overall child population, requiring an increased number of specialty care providers.

But funding to train the doctors to serve these children has not kept pace. While children under 18 currently comprise about 23 percent of the U.S. population, only 9 percent of all federal support for graduate medical education is targeted toward training pediatric providers (combining CHGME and Medicare funding for pediatric residents). "

Freestanding children's hospitals, which, as noted, train approximately half of all pediatricians and pediatric specialists, receive almost no federal GME support through Medicare. At the same time, CHGME funding has decreased 17 percent since FY 2010, from \$317.5 million to \$265 million in FY 2015, jeopardizing the ability of children's hospitals to train enough providers to meet children's needs. Furthermore, analysis commissioned by the Children's Hospital Association shows that at current funding levels, the average CHGME payment per full-time equivalent (FTE) resident represents only 43 percent of what Medicare GME provides to support training in adult teaching hospitals.

Additionally, serious pediatric workforce shortages persist, most acutely among pediatric subspecialties. Due to shortages, children's hospitals report the following wait times for scheduling appointments:

- Developmental pediatrics – Average wait time of 13 weeks
- Endocrinology – Average wait time of 10 weeks
- Neurology – Average wait time of nine weeks
- Pulmonology – Average wait time of eight weeks
- Gastroenterology – Average wait time of five weeks

Localized shortages of pediatric primary care also continue, particularly in certain rural areas. These shortages affect children's access to timely, appropriate care and underscore the importance of strong continued funding for CHGME.

The White House's FY 2016 budget proposes \$100 million in funding for CHGME, a year after proposing to eliminate funding for the program. While children's hospitals are pleased with restoration of funding for CHGME we remain very concerned the proposed funding level of \$100 million is inadequate to support the level of training necessary to protect access to care for children. CHGME has a 15-year track record of success, and underfunding it puts at risk the gains that have been made to date for children's health. This amount falls well short of the program's authorization level of \$300 million included in the bill signed into law by President Obama in 2014, and the \$265 million provided by congress for FY 2015. We hope in future budgets the Administration will be able to increase funding to similar levels, and we call on Congress to continue its history of strong bipartisan support of the program.

The potential effects of diminished support for pediatric training would be felt by children and their families, including those with rare and complex conditions. CHGME support has allowed children's hospitals to develop training programs in highly specialized disciplines that target the unique needs of children, including, for example, pediatric surgical oncology, radiation oncology, pediatric pathology and bone marrow transplantation. Only a small number of institutions provide training in some of these areas.<sup>iii</sup> Without strong CHGME support, it would be difficult for children's hospitals to maintain support for programs focused on these

subspecialties which are crucial to providing the highest quality of care for children facing rare and complex medical conditions. There are also several pediatric specialties (e.g. endocrinology, nephrology) that are at risk of sustaining tremendous losses as the current workforce retires and not enough new specialists are trained.

Even with CHGME, children's hospitals incur significant costs to subsidize their teaching mission, costs that can be as high as \$40 million annually in some children's hospitals. These additional costs are particularly difficult to bear given that children's hospitals are typically large Medicaid providers, with more than 50% of the average number of days of care being covered by Medicaid. Medicaid reimbursement levels in many states remain well below those of private insurance and other government programs, creating another significant fiscal challenge for children's hospitals, particularly as state Medicaid programs have been scaled back significantly in recent years. Reductions in CHGME dollars must often be offset from training experiences and patient care services that inevitably impact children's access to care and the future pediatric workforce.

Furthermore, there are no adequate substitutes for CHGME to support training at freestanding children's hospitals. Other potential sources of support, such as Medicaid GME—which has been significantly reduced or eliminated in many states—or competitive grant funding, are not available to many children's hospitals and cannot support training on the scale necessary to meet current and future workforce needs.

As a result of the decline in CHGME funding some hospitals have reported that their resident FTE level, which had been increasing in response to demand, has leveled off and now declined. Additionally, cuts have slowed the ability to grow in areas of need. Hospitals have reported, for instance, that they can only support half of the qualified rheumatology candidates that have applied. Other hospitals have indicated they are reevaluating the level of training that their fellowship programs will be able to provide, recognizing that the decrease in CHGME funding will likely force them to offer fewer training slots. The result will be fewer pediatric subspecialists across the country, given the significant role in training the next generation of specialists that CHGME hospitals play.

We recognize that the current budget climate is extraordinarily challenging and that Congress has a responsibility to carefully consider the nation's spending priorities. However, now is not the time to take a step backwards in pediatric medicine. The CHGME program is critical to protecting gains in pediatric health and ensuring access to care for children nationwide.

We respectfully request that the Subcommittee continue its history of bipartisan support for children's health and fund CHGME at its authorized funding level of \$300 million in the FY 2016 Labor-HHS appropriations bill.

The Children's Hospital Association, and the children and families we serve, thank you for your past support for this critical program and your leadership in protecting children's health.

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The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 children's hospitals, the Association is the voice of children's hospitals nationally. The Association champions public policies that enable hospitals to better serve children and is the premier resource for pediatric data and analytics, driving improved clinical and operational performance of member hospitals. Formed in 2011, Children's Hospital Association brings together the strengths and talents of three organizations: Child Health Corporation of America (CHCA), National Association of Children's Hospitals and Related Institutions (NACHRI) and National Association of Children's Hospitals (N.A.C.H.). The Children's Hospital Association has offices in Washington, DC, and Overland Park, KS.

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<sup>i</sup> 2014 report, "*Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children*", prepared for Children's Hospital Association by Dobson DaVanzo & Associates, p. vi.

<sup>ii</sup> Sources: U.S. Census Bureau; 2014 report, "*Comparative Analysis of GME Funding for Children's Hospitals and General Acute Care Teaching Hospitals*", prepared for Children's Hospitals Association by Dobson DaVanzo & Associates.

<sup>iii</sup> Children's Hospital Association fact sheet, "*Percentage of Pediatric Specialists Trained at CHGME Hospitals*", 2012.



**Testimony of Susan Ruzenski**

**Executive Director of the Helen Keller National Center**

**April 29, 2015**

The Helen Keller National Center (HKNC), authorized by the Helen Keller National Center Act (CFDA No. 84.128), is funded in the Department of Education budget reviewed by the Labor/HHS/Education Appropriations Subcommittees in the House and Senate. **The Center requests an increase from the current \$9.1 million to \$15 million for FY 2016.**

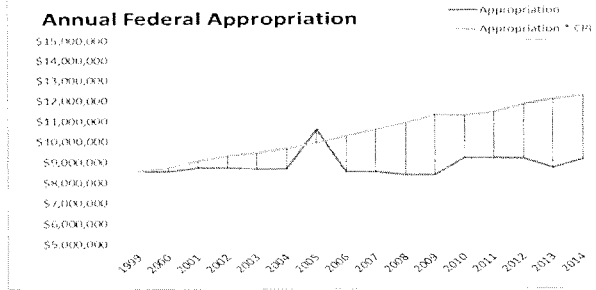
Authorized by a unanimous vote of Congress in 1967, HKNC's mission is to enable all legally deaf-blind citizens (totaling more than 1.2 million Americans) to live and work in their community of choice. HKNC operates the only comprehensive national vocational rehabilitation program exclusively serving both youth and adults who are deaf-blind. The Act mandates that the Center will:

- (1) Provide specialized intensive services, or any other services, at the Center or anywhere else in the United States necessary to encourage the maximum personal development of any individual who is deaf-blind;
- (2) Train family members of individuals who are deaf-blind at the Center or anywhere else in the United States, in order to assist family members in providing and obtaining appropriate services for the deaf-blind individual.
- (3) Train professionals and allied personnel at the Center or anywhere else in the United States to provide services to the deaf-blind.
- (4) Conduct applied research, development programs, and demonstrations with respect to communication techniques, teaching methods, aids and devices, and delivery of services; and
- (5) Maintain a national registry of individuals who are Deaf-Blind.

For more than forty-eight years, HKNC has fulfilled this mandate by: operating a comprehensive rehabilitation training program at its headquarters in Sands Point, NY; providing technical assistance, information, referral, advocacy, and training to local communities through its ten (10) regional offices and outreach programs; enhancing the ability of service providers to better meet the needs of people who are deaf-blind at the state and local levels by sponsoring research, disseminating information, and offering training to professionals nationwide.

HKNC has been level-funded for over 15 years. The graph shows what funding might have been if it had simply kept pace with the CPI.<sup>1</sup>

Lack of appropriate



funding resulted in the elimination of several staff positions supporting the comprehensive vocational rehabilitation program. Fewer people are being served annually and, regrettably, a model program providing employment skills training to deaf-blind Americans with intellectual disabilities has had to be discontinued. Further, HKNC could no longer sustain its widely lauded national affiliate network of over 40 state and private agencies which was built over two decades. This has had a severely negative impact on building a national infrastructure for deaf-blind services across the United States.

Lack of appropriate funding has significant implications not only for HKNC but more importantly for individuals identified as the most severely disabled and most underserved. In a 2007 report from the Research and Training Center at Mississippi State University, it was estimated that there are approximately 1.2 million people in the U.S. living with a combined vision and hearing loss, the overwhelming majority of who are 55 years of age or more. In June 2011, the WESTAT Corporation completed a two year evaluation of HKNC on behalf of the U.S. Department of Education's Rehabilitation Services Administration. Among its conclusions were that, "*HKNC [is] meeting its mandate to provide services to any deaf-blind individual,*

<sup>1</sup> FY05 appropriation included small increase to approx. \$11 million. It is unclear whether this one-time increase was disbursed by the Dept. of Education.

*family members, and service providers, and conduct applied research and demonstrations” and that, “the preponderance of evidence from multiple data sources indicates that HKNC is providing services to address the vocational and independent living needs of deaf-blind individuals, and many stakeholders familiar with HKNC’s work consider HKNC to be the ‘gold standard’ for provision of services to deaf-blind individuals.* The WESTAT evaluation indicated that state VR agencies generally lack services and resources for individuals who are deaf-blind, further reconfirming the necessity for HKNC’s work in millions of Americans’ lives.

Those returning to their home communities upon completion of training, ready and able to work, need follow up services such as job development and job placement services. Expanding HKNC Field operations will create an extended service option that will impact an individual’s successful vocational outcome and life in their home community. The creation of a national infrastructure to address the unmet needs of individuals with combined vision and hearing loss, their family members, and the professionals who work with the deaf-blind community can happen when HKNC has the resources to play a pivotal role in cultivating and maintaining a collaborative affiliate within each state. Our affiliate network once included 42 separate agencies and community partners, located in 34 states across the nation. This network provided HKNC students with increased services in their home communities and coordinated increased research and knowledge sharing amongst practitioners. Greater federal investment will permit HKNC to partner with researchers, universities, private and state agencies, and consumer organizations to rebuild capacity and to reestablish needed services nationally. The shortage of highly qualified personnel in Special Education and Rehabilitation is well documented and is now at crisis levels especially for disabilities such as Deaf-Blindness.

The Federal Government recently set aside up to \$10 million annually for the National Deaf-Blind Equipment Distribution Program (NDBEDP), which provides for the training and purchase of telecommunications equipment for deaf-blind Americans. With the passage of the Communications Video and Accessibility Act of 2010, those with combined vision and hearing loss are now afforded equal access to telecommunications. Recent advances in technology have led to greater community participation and opportunities for employment in careers that were not thought possible as recently as ten years ago. This federal involvement cannot be effective if individuals who are deaf-blind do not have access to highly skilled assistive technology instructors. Here again, an increased appropriation will leverage already existing talent and resources at HKNC to maximize Federal impact.

With short-term funding from two private foundations, HKNC has been able to implement two important programs to address the crucial need for qualified personnel. The first is a “train the trainer” program preparing assistive technology instructors to serve deaf-blind citizens on the use of equipment available through the NDBEDP, including iOS smart devices and refreshable Braille displays. The second is the Information, Research and Professional Development (IRPD) Department at HKNC which was created to expand HKNC Professional Learning opportunities through distance learning. Professionals can receive ongoing development opportunities in a myriad of critical rehabilitation disciplines such as adaptive technology, touch signals, employment skills, orientation and mobility and independent living development. The IRPD also conducted five state wide needs assessments to clearly identify unmet needs. With this rich data across geographic regions targeted professional development activities have been identified. Unfortunately, with both grants funded only through 2015 at total amounts exceeding two million dollars annually, these essential projects must be halted, leaving

their great promise unless permanent funding is provided through an increase in the Federal appropriation.

Deaf-Blind people across the country are contributing to their communities, holding down jobs in a wide range of careers, and enjoying full, rich, productive lives. We can only continue this mission of building robust local capacity throughout the US with the right resources. A \$6 million increase in funding is essential to enable HKNC to address, on a national level, the unmet and growing needs of the deaf-blind community. We aim to:

1. Re-construct a national affiliate network of service providers working with individuals with a combined vision and hearing loss.
2. HKNC will invest in four states (determined through an RFP process) to broaden and strengthen service options by developing a core group of trained rehabilitation professionals in each, using an established Community Services model. HKNC will strengthen its national collaborative approach to service delivery through ongoing professional and consumer partnerships.
3. Offer an array of professional training programs, products, curriculum development, and distance learning to boost the number of professionals trained to work with individuals with combined vision and hearing loss.
4. Provide further research documenting needs and trends in the deaf-blind community.
5. Maintain and enhance our capacity to offer comprehensive vocational rehabilitation services.

Additional federal funding is essential for HKNC to assist people who are deaf-blind to break through the barriers of isolation and marginalization. We urge the Subcommittee to give them this deeply needed opportunity.

**Institution:** National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)

**Submitted by:** Dr. Gerard Buckley, President, NTID; Vice President and Dean, RIT

**Email:** gbuckley@ntid.rit.edu

**Phone:** (585) 475-6317

Created by Congress in 1965, the National Technical Institute for the Deaf (NTID) is a “Special Institution” in the federal budget (under the Department of Education) as well as one of nine colleges of RIT, in Rochester, N.Y. We provide a university technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals. On behalf of NTID, for FY 2016, I would like to request \$68,451,000, for Operations. With our history of successful stewardship of federal funds and outstanding educational record of service with people who are deaf and hard of hearing, NTID is a federal investment that *works*.

### **Enrollment:**

NTID students are part of a university (RIT) that includes more than 16,000 hearing studying at the associate, baccalaureate, master’s and doctoral levels. Truly a national program, NTID has enrolled students from all 50 states. In Fall 2014 (FY 2015), NTID’s enrollment was 1,387 students. For FY 2016, NTID hopes to maintain an enrollment near 1,400, if our operational resources allow us to do so. NTID’s enrollment history over the last 10 years is shown on the next page.

**NTID Enrollments: FY 2006 – FY 2015**

<b>Fiscal Year</b>	<b>Deaf/Hard-of-Hearing Students</b>				<b>Hearing Students</b>			<b>Grand Total</b>
	<b>Undergrad</b>	<b>Grad RIT</b>	<b>MSSE</b>	<b>Sub-Total</b>	<b>Interpreting Program</b>	<b>MSSE</b>	<b>Sub-Total</b>	
<b>2015</b>	1,153	44	16	1,213	146	28	174	1,387
<b>2014</b>	1,195	42	18	1,255	147	30	177	1,432
<b>2013</b>	1,269	37	25	1,331	167	31	198	1,529
<b>2012</b>	1,281	42	31	1,354	160	33	193	1,547
<b>2011</b>	1,263	40	29	1,332	147	42	189	1,521
<b>2010</b>	1,237	38	32	1,307	138	29	167	1,474
<b>2009</b>	1,212	48	24	1,284	135	31	166	1,450
<b>2008</b>	1,103	51	31	1,185	130	28	158	1,343
<b>2007</b>	1,017	47	31	1,095	130	25	155	1,250
<b>2006</b>	1,013	53	38	1,104	116	36	152	1,256

(In chart above, MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing; Grad RIT: other graduate programs at RIT.)

**NTID Academic Model:** NTID offers high quality, career-focused associate degree programs preparing students for well-paying technical careers. NTID also provides transfer associate degree programs to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including sign language interpreting, real-time speech-to-text captioning, and notetaking) as well as tutoring services. NTID also requires a cooperative education (co-op) component as an integral part of academic programming that prepares students for success in the job market. Last year, 238 students participated in 10-week co-op experiences that augmented their academic studies, refined their social skills, and prepared them for the competitive working world.

**Student Accomplishments:** NTID deaf and hard-of-hearing students persist and graduate at higher rates than the national persistence and graduation rates for all students at two-year and four-year colleges. Over the past five years, an average of 92% of our graduates found jobs commensurate with their education level. Of our FY 2013 graduates, 94% were employed one year later, with 60% employed in business and industry, 31% in education/non-profits, and 9% in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In FY 2012, NTID, the Social Security Administration, and Cornell University examined earnings and federal program participation data for approximately 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a higher rate and earn more (therefore paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI and SSDI than students who withdrew from NTID.

Using SSA data, at age 50, 78% of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73% with associate degrees report earnings, compared to 58% of NTID deaf and hard-of-hearing students who withdrew from NTID and 69% of deaf and hard-of-hearing graduates from other universities. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, \$58,000



is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and \$41,000 for those with associate degrees, compared to \$34,000 for deaf and hard-of-hearing students who withdrew from NTID and \$21,000 for deaf and hard-of-hearing graduates from other universities.

An NTID education also translates into reduced dependency on federal transfer programs, such as SSI and SSDI. At age 40, less than 2% of NTID deaf and hard-of-hearing associate and bachelor degree graduates participate in the SSI program compared to 8% of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18% of NTID deaf and hard-of-hearing bachelor degree graduates participate in the SSDI program and 28% of deaf and hard-of-hearing associate degree graduates participate in the SSDI program, compared to 35% of deaf and hard-of-hearing students who withdrew from NTID.

**Budget Request Justification:** NTID has worked hard to manage its resources carefully and responsibly. As of Fall 2014, NTID's workforce had been reduced by almost 8% as compared to pre-sequestration levels with a corresponding 13% decrease in personnel compensation costs. In terms of non-federal revenues, from FY 2010 to FY 2015, student tuition and fees increased by 37% to offset the rising costs of providing a state-of-the-art college education. Additionally, from FY 2006 to FY 2014, NTID raised approximately \$21 million in support from individuals and organizations.

NTID's FY 2016 request of \$68,451,000 in Operations would allow NTID to admit all qualified students for Fall 2016 enrollment, keep the FY 2016 tuition increase relatively low (3-4%), and continue to offer Grants in Aid to more students. With this funding, NTID can continue to hire and maintain crucial positions that support our students, such as sign-language interpreters, captionists, audiologists, etc. Some of these positions were cut as a result of sequestration, causing large waiting lists for these services. With this FY 2016 request, NTID can continue to propose new technical programs for our students, purchase the cutting-edge equipment necessary for their success, and ensure 40-year-old classroom spaces are meeting their needs.

NTID students persist and graduate at higher rates than national rates for all students. NTID graduates have higher salaries, pay more taxes, and depend less on federal SSI/SSDI payments. Our employment rate is 92% over the past five years. Therefore, I ask that you please consider funding our FY 16 request of \$68,451,000 for Operations. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens.

**Testimony of Michael Rose**  
**Associate Director for Government Relations**  
**National Association for College Admission Counseling (NACAC)**  
**Labor-Health and Human Services-Education Subcommittee**  
**House Appropriations Committee**  
**April 29, 2015**

Chairman Cole, Ranking Member DeLauro and Members of the Subcommittee, on behalf of the National Association for College Admission Counseling (NACAC), thank you for the opportunity to submit testimony regarding the Fiscal Year 2016 Labor-Health and Human Services-Education appropriations bill. NACAC urges at least level funding for the Department of Education's GEAR UP and the TRIO programs and the Elementary and Secondary School Counseling Program. It also calls for adequate funding for the Department of Education's financial aid programs.

Founded in 1937, NACAC is an organization of more than 13,000 professionals from around the world dedicated to serving students as they make choices about pursuing postsecondary education. NACAC is committed to maintaining high standards that foster ethical and social responsibility among those involved in the transition process, as outlined in the NACAC Statement of Principles of Good Practices (SPGP), which can be found on our website ([www.nacacnet.org](http://www.nacacnet.org)). Our members include school counselors, college admissions officers, independent educational consultants, community-based organizations, counselor educators, among others. Regardless of where we hang our hat, our goals are the same: to help students navigate the admissions process and enroll in a college or university that meets his or her needs.

As you well know, the importance of a college degree is increasing each day. During the many hearings you will hold on the FY16 budget, I am sure that you will hear dozens of statistics. I

would like to remind you of a couple that are, arguably, the most important to families in your Districts and the future of our nation:

- According to the Department of Education, ninety percent of the fastest growing jobs in America require a postsecondary credential or training, yet only 41 percent, or 11.5 million, of 18-24 year olds were enrolled in college in 2008 according to the American Association of State Colleges and Universities. To put that in perspective, it is estimated that by 2018, the United States economy will face a shortage of at least 3 million post-secondary degrees;
- The Georgetown Center on Education and the Workforce reports that graduates who earn a bachelor's degree or higher can be expected to earn 74 percent more over a lifetime than those who only complete high schools; and
- The Alliance for Excellent Education reported that the nearly 1.2 million high school dropouts from the class of 2008 represent a \$319 billion loss to the economy in lifetime earnings. It went on to say that reducing the dropout rate by 50 percent for a single high school class would result in home sales totaling as much as \$10.5 billion and auto sales totaling \$340 million.

In short, helping students graduate high school and attend college, either at a 2 year or 4 year institution, is good for families and our economy. Based on NACAC's research and collaborations with thirty other organizations in the Pathways to College Network, we have identified two major policy areas to improve college access: quality counseling and need-based financial aid.

Access to quality counseling is a crucial component of students' post-secondary educational planning and enrollment. High school students have many options available to them; but there are also a lot of question students must answer as they decide which college to attend; the most critical being what type of college is best for him/her and how to pay for it. Guidance counselors are crucial to helping students answer these questions and help student make smart decisions about their future. Therefore, we urge the Subcommittee to at least maintain funding for GEAR UP and TRIO in FY2016 as the programs currently receives. These programs provide college counseling and early awareness services that are invaluable to students from low-income families, many of whom are the first in their families to consider attending college.

In addition, we urge the Subcommittee to at least maintain funding for the Elementary and Secondary School Counseling Program (ESSCP) in FY2016 as it received in FY15 so that funds are available to secondary schools. The ESSCP is the *only* federal program devoted to creating and expanding counseling programs in schools. In addition to providing critical support for with social, emotional, and behavioral issues, counselors provide students with college and career counseling as they transition into adulthood. As part of the No Child Left Behind Act, Congress expanded the ESSCP to include secondary school activities. However, due to the program's statutory funding trigger, secondary schools cannot benefit unless total funding exceeds \$40 million, with that base amount reserved for elementary schools. This funding trigger has been met each year since FY 2008, which has allowed middle and high schools to apply for grants. I would note that in the recent markup of the Elementary and Secondary Education Act (formally titled *Every Child Achieves Act of 2015*), an amendment to reauthorize the ESSCP program received bipartisan support.

Currently ratios of school counselors to students far exceed the recommendations of the professional organizations that represent them. The recommended ration is 250 students to 1 counselor; in Oklahoma, the ratio is 409 to 1 and in Connecticut the ratio is 518 to 1. Grants awarded through ESSCP help reduce these ratios, ensuring that students receive high quality counseling when they need it. We urge the Subcommittee to at least maintain the level of funding for ESSCP in FY16.

Another important component of college access is affordability. According to the Department of Education, for the 2010–11 academic year, annual prices for undergraduate tuition, room, and board was approximately \$13,600 at public institutions and \$36,300 at private institutions. Between 1999–2000 and 2010–11, prices for undergraduate tuition, room, and board at public institutions rose 42 percent, and prices at private institutions rose 31 percent, after adjustment for inflation.

Unfortunately, the steadily increasing costs coupled with the struggling economy are making it difficult for many students to attend college. Federal financial aid programs are the most successful aid programs available to students. These programs provide students with the means to a degree without saddling them with massive debt which often results from private loans.

Therefore, we strongly urge you to at least maintain investment in the Pell Grant so that the maximum award keeps pace with the cost of postsecondary education and to avoid a shortfall. We also encourage the Subcommittee to provide funding for other need-based aid programs,

including Supplemental Educational Opportunity Grants (SEOG) and Work Study, to help make college more affordable to students.

These programs are key to making college affordable for students. As you know, businesses throughout the country are seeking educated, highly skilled workers. Unfortunately, the demand for these workers outstrips supply and this trend will only increase if students are unable to afford college. NACAC recognizes that our country faces incredible fiscal challenges; however, we strongly believe that these programs are critical to preparing our students to enter the workforce, leading to a more productive workforce, increase tax revenues, all of which will help address our nation's fiscal problems.

Again, thank you for the opportunity to provide written testify to the House Appropriations Committee. I am happy to answer any questions you might have. I can be reached at 703.299.6817 or [mrose@nacacnet.org](mailto:mrose@nacacnet.org).



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**Position Statement on the FY 2016 Budget Request for the  
National Institutes of Health (NIH) submitted by the  
ASME NIH Task Force**

**April 29, 2015**

ASME is a non-profit technical and educational organization with over 140,000 members worldwide. The Society's members work in all sectors of the economy, including industry, academia, and government. The ASME NIH Task Force ("Task Force") of the ASME Inter-Sector Committee on Federal Research and Development is pleased to provide comments on the bioengineering-related programs contained within the National Institutes of Health (NIH) Fiscal Year (FY) 2016 budget request. The Task Force is focused on the application of mechanical engineering knowledge, skills, and principles for the conception, design, development, analysis and operation of biomechanical systems.

**The Importance of Bioengineering**

Bioengineering is an interdisciplinary field that applies physical, chemical, and mathematical sciences, and engineering principles to the study of biology, medicine, behavior, and health. It advances knowledge from the molecular to the organ levels, and develops new and novel biologically derived medications and devices, materials processes, implants, and informatics approaches for the prevention, diagnosis, and treatment of disease, for patient rehabilitation, and for improving health. Bioengineers have employed mechanical engineering principles in the development of many life-saving and life-improving technologies, such as the artificial heart, prosthetic joints, diagnostics, and numerous rehabilitation technologies.

**Background**

The NIH is the world's largest organization dedicated to improving health through medical science. For the last five decades the NIH has played a leading role in the major breakthroughs that have increased average life expectancy by 15 to 20 years.

The NIH is comprised of different Institutes and Centers that support a wide spectrum of research activities including basic research, disease and treatment-related studies, and epidemiological analyses. The mission of individual Institutes and Centers varies from either study of a particular organ (e.g. heart, kidney, eye), a given disease (e.g. cancer, infectious diseases, mental illness), a stage of life (e.g. childhood, old age), or finally it may encompass crosscutting needs (e.g., sequencing of the human genome). The National Institute of Biomedical Imaging and Bioengineering (NIBIB) focuses on the development, application, and acceleration of biomedical technologies to improve outcomes for a broad range of health care challenges.

**FY 2016 NIH Budget Request**

The total FY 2016 NIH budget request is \$31.3 billion, a 3.3 percent increase over FY 2015 enacted amounts. The Task Force recognizes the Administration's commitment to reducing the



federal deficit but this increase barely outpaces the inflation rate. According to the Biomedical Research and Development Price Index (BRDPI), the projected increase in medical research costs due to inflation is 2.4 percent. This inflationary pressure is compounded by the stagnant budgets for the NIH over the last few years, resulting in a significant decrease in funding for the NIH over the past few fiscal years.

NIH is enacting policies to guide investments while limiting the impact of these inflationary cost increases, including a six percent increase in the average cost of competing and non-competing Research Project Grants (RPGs); flat funding for Research Centers and Other Research; and a one percent increase for Intramural Research and Research Management and Support; and constraints on staffing levels. However, these policies alone are not sufficient to offset the need for additional support for critical areas of health research, especially given the reduction in funding and the high inflation rate of medical research costs over the last several years. We therefore fully support the President's proposed FY 2016 budget as an absolute minimum level for the NIH given current budget constraints, but recommend out-year budget increases well beyond BRDPI inflation rates to compensate for the erosion of medical research funding the agency has experienced over the last few years.

NIBIB estimates 626 competitive Research Project Grants (RPG) will be supported under the FY16 budget, an increase of 48 grants. The Task Force commends NIBIB's focus on increasing the number of new RPGs in FY16 because as this could significantly benefit future researchers in a program that has been considered tight for funding opportunities.

#### **NIBIB Research Funding**

The Administration's FY 2016 budget request supports \$337.3 million for the NIBIB, a three percent increase over the FY15 enacted amount. The mission of the NIBIB is to seek to improve human health by leading the development and application of emerging and breakthrough technologies based on a merging of the biological, physical, and engineering sciences. As noted above, this relatively flat funding is compounded by the 2.4 percent projected increase in research costs due to inflation predicted by the BRDPI index for FY 2016.

The budget for NIBIB Research Grants would increase slightly from \$212.4 million to \$226 million, a 6.4 percent increase. Funding for intramural research would be held flat at \$12 million. NIBIB's Research Management and Support request is \$19.7 million, a one percent increase from the FY 2015 amount.

NIBIB funds the Applied Science and Technology (AST) program, which supports the development and application of innovative technologies, methods, products, and devices for research and clinical use that transform the practice of medicine. The FY 2016 request for AST is \$158.6 million, a 4.3 percent increase from FY15.

Additionally, NIBIB funds the Discover Science and Technology (DST) program, which is focused on the discovery of innovative biomedical engineering and imaging principles for the benefit of public health. The FY16 request for DST is \$101.6 million, a 7.9 percent increase from FY15.

The Technological Competitiveness-Bridging the Sciences program, which funds interdisciplinary approaches to research, would receive \$22.4 million in FY16, also a one percent increase from FY15.

### **Task Force Recommendations**

The Task Force is concerned that the United States faces rapidly growing challenges from our counterparts in the European Union and Asia with regards to bioengineering advancements. While total health-related US research and development investments have expanded significantly over the last decade, investment in bioengineering at NIBIB has remained relatively flat over the last several years.

The Task Force wishes to emphasize that, in many instances, bioengineering-based solutions to health care problems can result in improved health outcomes and reductions in health care costs. For example, coronary stent implantation procedures cost approximately twenty thousand dollars, compared to bypass graft surgery at double the cost. Stenting involves materials science (metals and polymers), mechanical design, computational mechanical modeling, imaging technologies, etc. that bioengineers work to develop. Not only is the procedure less costly, but the patient can return to normal function within a few days rather than the months often required to recover from bypass surgery, greatly reducing other costs to the economy. NIBIB research is also helping to commercialize new technologies, such as new low-cost ultrasound imaging systems, which became commercially available after just seven years in development. NIBIB-funded research and development also support health care decision support systems for physicians that provide the latest evidence-based practices, improve consistency of care, reduce patient risk, helping to deliver health care solutions more safely and effectively and decreasing overall costs by up to 17% in pilot programs. Therefore, we strongly urge Congress to consider increased funding for bioengineering within the NIBIB and across NIH, and to work to strengthen these investments in the long run to reduce US health care costs and support continued US leadership in bioengineering.

Even during these challenging fiscal times, the NIBIB must obtain sustained funding increases, both to accelerate medical advancements as our nation's population ages, and to mirror the growth taking place in the bioengineering field. Data on NIH economic benefits indicate a three to five dollar return to the economy for every one dollar invested in research. In addition, the NIH has an important feeder effect on small companies clustered around academic research institutions. NIBIB funding plays a unique role in this health care innovation system due to its continued focus on technological development and high-risk, high-reward research. The Task Force believes that the Administration's budget request for FY 2016 is not aligned with our long-term national health care challenges; a flat or reduced budget will not keep up with current inflationary increases for biomedical research, eroding the United States' ability to lay the groundwork for the medical advancements of tomorrow.

While the Task Force supports efforts to continue ramping up federal investments in research and development in the physical sciences, we believe that strong federal support for bioengineering and the life sciences is also essential to the health and competitiveness of the United States. Congress and the Administration should work to develop a specific plan, beyond

President Obama's call for 'innovations in health care technology' to focus on specific and attainable medical and biomedical research priorities which will reduce the costs of health care and improve health care outcomes. Further, Congress and the Administration should include in this strategy new mechanisms for partnerships between NSF and the NIH to promote bioengineering research and education. Finally, the federal research budget should provide long-term projections in order for researchers can plan accordingly. The Task Force feels these initiatives are necessary to build capacity in the US bioengineering workforce and improve the competitiveness of the US bioengineering research community.

###

ASME International is a non-profit technical and educational organization with over 140,000 members worldwide. The Society's members work in all sectors of the economy, including industry, academia, and government. This position statement represents the expert views of the NIH Task Force of the Inter-Sector Committee on Federal Research and Development and is not necessarily a position of ASME as a whole.

## Maryland Center for Developmental Disabilities

at Kennedy Krieger Institute

April 29, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chair Cole and Ranking Member DeLauro:

On behalf of the Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute, I want to write to express my strong support for continued appropriations to the Department of Health and Human Services for activities promoting community integration for individuals with disabilities. The MCDD is one of a network of 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) that provide interdisciplinary pre-service preparation of students and fellows, continuing education, community training, research, model services, technical assistance, and information dissemination. Our mission is to provide leadership to promote inclusion of individuals with intellectual, developmental, and other disabilities in their communities.

We understand that one organization has urged its members to demand language in the Labor, HHS, Education and Related Agencies appropriations bill that would prohibit the use of HHS funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is extremely troubling and counter to the Supreme Court's landmark decision in *Olmstead v. L.C.*, often referred to as the *Brown v. Board of Education* of the disability community.

Enforcement of the ADA's integration mandate and the *Olmstead* decision is a top priority for the disability community. *Olmstead* enforcement efforts in recent years have brought some of the most significant improvements to the lives of people with disabilities in decades. Thousands of individuals with disabilities have, for the first time, been given opportunities to live in their own homes and communities, with privacy, dignity, and independence. They have been able to participate as full members of society.

Similarly, implementation of the new rules concerning Medicaid-financed home and community-based services is important to ensure that disability service systems support the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Maryland Center for Developmental Disabilities  
at Kennedy Krieger Institute



Maryland Center for Developmental Disabilities  
at Kennedy Krieger Institute  
*Maximizing Potential. Creating Change.*

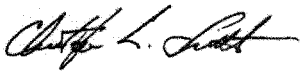
For more information, visit [www.mcdd.kennedykrieger.org](http://www.mcdd.kennedykrieger.org) or call 443-923-9555.

Neither *Olmstead* enforcement nor implementation of the Medicaid home and community-based services rules deprives anyone of the choice to live in an institution. Instead, *Olmstead* and the Medicaid rules offer thousands of individuals and their families the *option* of choosing home and community-based service settings—an option that has been unavailable for far too long. No one is forced to move to a community setting against his or her wishes.

Inclusion of any language prohibiting use of congressional appropriations for enforcement of regulations governing HCBS settings would deprive people with disabilities of choice and force them to live and receive services in restricted and segregated settings. We urge you **NOT** to include this language in the appropriations bill.

People with disabilities (and their families and advocates) have fought hard for decades for the opportunity to live, work, and receive services in integrated settings. Please do not take those options away.

Sincerely,

A handwritten signature in black ink, appearing to read "Chris L. Smith".

Christopher L. Smith, Ph.D., Director, Assistant Professor  
Maryland Center for Disabilities (MCDD)

Kennedy Krieger Institute

Phone: 443-923-9555

Fax: 443-923-9570

Email: [smithchr@kennedykrieger.org](mailto:smithchr@kennedykrieger.org)



TESTIMONY ON THE FY 2016 BUDGET BY

LAWRENCE MEHREN, CHIEF EXECUTIVE OFFICER, ACCELERATE DIAGNOSTICS, INC.

TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGENCIES, APRIL 22, 2015

Chairman Cole, Representative DeLauro and members of the Subcommittee, thank you for the opportunity to submit testimony on the Fiscal Year 2016 budget. I am Lawrence Mehren, Chief Executive Officer of Accelerate Diagnostics, Inc., of Tucson, Arizona, an *in vitro* diagnostics company dedicated to providing solutions to the global challenge of antibiotic resistant organisms. In view of the growing public health crisis related to untreatable bacterial infections, we urge Congress to provide funds to implement the National Strategy to Combat Antibiotic Resistant Bacteria and support the Centers for Disease Control's Antibiotic Resistance Solutions Initiative. We support the following HHS budget requests:

Centers for Disease Control and Prevention (CDC): Antibiotic Resistance Solutions Initiative (\$264 million); National Healthcare Safety Network (NHSN) (\$32 million); Advanced Molecular Detection (AMD) Initiative (\$30 million)

National Institutes of Health (NIH): National Institute of Allergy and Infectious Diseases (NIAID) (\$4.615 billion with an increase of \$100 million to spur rapid diagnostics R&D)

HHS Assistant Secretary for Preparedness and Response (ASPR): Biomedical Advanced Research and Development Authority (BARDA) (\$522 million)

Each year in the United States at least two million people are infected with bacteria that are resistant to antibiotics; some 23,000 die as a direct result of these infections. This represents an immediate and growing crisis that threatens public health and national security, warranting increased federal funding to deal with antibiotic resistance (AR).

In particular, there is a critical need for improved AR diagnostic technologies, including rapid identification (ID) of pathogens, and high speed antibiotic susceptibility testing (AST). These are key to effective patient treatment, stewardship of life-saving antibiotic drugs, and reduced healthcare costs. Additionally, Congress should encourage adoption and utilization of new diagnostic technologies, with education of physicians and pharmacists, as well as appropriate reimbursement.

Hospitalized patients with bacterial infections typically endure 2-3 day delays before current microbiology laboratory methods reveal the specific pathogen and optimal antibiotic therapy. Before that, broad spectrum, empiric antibiotics are typically administered in the hope that they will be effective against the infection in the particular patient.

The result: delayed optimal treatment, greater patient distress, poorer outcomes, higher treatment costs and dilution of antibiotic effectiveness (as microbes adapt to them). All of these are obviously unacceptable.

Accelerate Diagnostics is developing an ID/AST system that identifies pathogens within one hour, and, using computer-controlled microscopy and image analysis

software, pinpoints the effective antibiotic within five hours from the availability of the sample.

The Accelerate ID/AST system includes four key technologies:

- Automated sample preparation
- Fluorescence In Situ Hybridization for quantitative and definitive bacterial identification
- Automated, time-lapse microscopy of immobilize bacterial cells challenged with antibiotics for susceptibility testing
- High-powered image analysis of bacterial growth and associated algorithms for Minimum Inhibitory Concentration (MIC) and antibiotic susceptibility determination

Accelerate plans to support the medical community with rapid diagnostic information for a broad range of infection types including bloodstream infections (septicemia), pneumonia, skin and wound infections as well as urinary tract infections.

Our company is entering into preclinical studies with our ID/AST platform in preparation for its registration trial for positive blood culture specimens. Accelerate recently entered into a research collaboration with the Rapid Antimicrobial Susceptibility Testing Laboratory at the CDC to develop tests for the rapid analysis of antibiotic-resistant biothreat agents based on this same platform. In a project funded by NIH, the Denver Health Medical Center will use the Accelerate ID/AST System to develop



a test to detect CRE directly from blood, with corresponding antibiotic susceptibility, in less than three hours.

Following are summaries of the budget items we support:

Centers for Disease Control and Prevention (CDC)

- Antibiotic Resistance Solutions Initiative (\$264 million), for prevention programs in all 50 states and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics; and for a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria
- National Healthcare Safety Network (NHSN) (\$32 million), for expansion of the Network to more than 17,000 facilities, providing real-time data about antibiotic use and trends, targeting health care facilities that need additional assistance using NHSN data, and implementing prevention strategies
- Advanced Molecular Detection (AMD) Initiative (\$30 million), allowing CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population, to effectively guide public health action

National Institutes of Health (NIH)

- National Institute of Allergy and Infectious Diseases (NIAID) (\$4.615 billion), including an increase of \$100 million to spur R&D for new rapid diagnostics to help ensure that antibiotics are prescribed appropriately, develop a national database of genome

sequence data of all reported human infections with antimicrobial-resistant microorganisms, launch a large-scale effort to better understand drug resistance, and create a rapid-response clinical trial network to test new antibiotics on individuals infected with highly resistant strains

HHS Assistant Secretary for Preparedness and Response (ASPR)

- Biomedical Advanced Research and Development Authority (BARDA) (\$522 million), including \$192 million dedicated to antimicrobial R&D, utilizing public-private partnerships to address the market failure in antibiotic R&D


Investing in AR will have a profound effect. CDC Director Tom Frieden projects that with proper funding, over five years the CDC can prevent at least 600,000 multi-drug-resistant infections, prevent at least 37,000 deaths from multi-drug resistant organisms and avert nearly \$8 billion in healthcare costs.

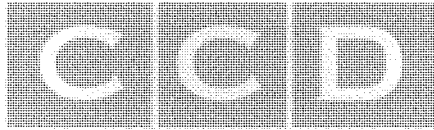
We would be delighted to meet with members of the committee or staff to provide further details and respond to your questions. Thank you for your consideration.



Lawrence Mehren  
Chief Executive Officer

3950 S. Country Club Road, Suite 470, Tucson, AZ 85714 520.365.3100





**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

April 28, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chair Cole and Ranking Member DeLauro:

On behalf of the Consortium for Citizens with Disabilities (CCD) Rights Task Force, we write to express our strong support for continued appropriations to the Department of Health and Human Services for activities promoting community integration for individuals with disabilities. CCD is a coalition of national disability organizations working for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

The activities of HHS, including the Centers for Medicare and Medicaid Services' enforcement of its rules concerning home and community-based services, as well as those of HHS component agencies such as the Administration on Intellectual and Developmental Disabilities and its grantees—including implementation and enforcement of the Americans with Disabilities Act and its integration mandate—are widely supported and critically important to improving the lives, independence and well-being of individuals with disabilities.

We understand that one organization has urged its members to demand language in the Labor, HHS, Education and Related Agencies appropriations bill that would prohibit the use of HHS funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is extremely troubling and counter to the Supreme Court's landmark decision in *Olmstead v. L.C.*, often referred to as the *Brown v. Board of Education* of the disability community.

Enforcement of the ADA's integration mandate and the *Olmstead* decision is a top priority for the disability community. *Olmstead* enforcement efforts in recent years have brought some of the most significant improvements to the lives of people with disabilities in decades. Thousands of individuals with disabilities have, for the first time, been given opportunities to live in their own

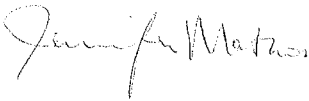
homes and communities, with privacy, dignity, and independence. They have been able to participate as full members of society.

Similarly, implementation of the new rules concerning Medicaid-financed home and community-based services is important to ensure that disability service systems support the community-based services and supports overwhelmingly favored by people with disabilities and their families.

Neither *Olmstead* enforcement nor implementation of the Medicaid home and community-based services rules deprives anyone of the choice to live in an institution. To the contrary, *Olmstead* and the Medicaid rules offer thousands of individuals and their families the *option* of choosing home and community-based service settings—an option that has been unavailable for far too long. No one is forced to move to a community setting against his or her wishes.

Inclusion of any language prohibiting the use of congressional appropriations for enforcement of regulations governing HCBS settings or for *Olmstead* enforcement or implementation would deprive people with disabilities of meaningful choices. We urge you not to include this language in the appropriations bill. People with disabilities have fought hard for decades for the opportunity to live, work, and receive services in integrated settings. Please do not take those options away.

Sincerely,



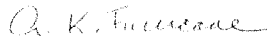
Jennifer Mathis  
Bazelton Center for Mental Health Law



Mark Richert  
American Foundation for the Blind



Dara Baldwin  
National Disability Rights Network



Sandy Finucane  
Epilepsy Foundation of America



Samantha Crane  
Autistic Self Advocacy Network

Co-chairs, CCD Rights Task Force



## American Association on Health & Disability

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T. 301-545-6140 F. 301-545-6144 [www.aahd.us](http://www.aahd.us)

**AAHD** · Dedicated to better health for people with disabilities through health promotion and wellness

April 28, 2015

Representative Tom Cole  
Chair, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2467 Rayburn House Office Bldg.  
Washington, D.C. 20515

Representative Rosa DeLauro  
Ranking Member, Subcommittee on Labor,  
Health & Human Services,  
Education and Related Agencies  
Committee on Appropriations  
2413 Rayburn House Office Bldg.  
Washington, D.C. 20515

Dear Chair Cole and Ranking Member DeLauro:

**RE: Continued Appropriations for HHS Activities Promoting Community Integration for Individuals with Disabilities**

The American Association on Health and Disability (AAHD) ([www.aahd.us](http://www.aahd.us)) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities.

**AAHD endorses the Consortium for Citizens with Disabilities (CCD) Task Force on Rights letter submitted to the subcommittee on this topic on April 28, 2015.**

The activities of HHS, including the Centers for Medicare and Medicaid Services' enforcement of its rules concerning home and community-based services, as well as those of HHS component agencies including implementation and enforcement of the Americans with Disabilities Act and its integration mandate—are widely supported and critically important to improving the lives, independence and well-being of individuals with disabilities.

We understand that one organization has urged its members to demand language in the Labor, HHS, Education and Related Agencies appropriations bill that would prohibit the use of HHS funds for any activities that might downsize Medicaid-funded institutions serving individuals with intellectual disabilities. Such language is extremely troubling and counter to the Supreme Court's landmark decision in *Olmstead v. L.C.*, often referred to as the *Brown v. Board of Education* of the disability community.

Inclusion of any language prohibiting the use of Congressional appropriations for enforcement of regulations governing HCBS settings or for *Olmstead* enforcement or implementation would deprive people with disabilities of meaningful choices. We urge you not to include this language in the appropriations bill. People with disabilities have fought hard for decades for the opportunity to live, work, and receive services in integrated settings. Please do not take those options away.

Sincerely,



E. Clarke Ross, D.P.A.  
Public Policy Director  
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301 545-6144 (fax)  
[rcarlin@aaahd.us](mailto:rcarlin@aaahd.us)

Testimony by

Carole L. Sherman

Before

Committee on Appropriations  
Subcommittee on Labor, HHS, Education & Related Agencies  
United States House of Representatives  
on  
Fiscal Year 2016

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Title/Institutional Affiliation	Mother & Co-Guardian of John; Volunteer advocate; Public Affairs Chairman, Families & Friends of Care Facility Residents (FF-CFR), Arkansas' statewide parent-guardian association, a 501 (c) 3 organization
Agency/Programs	Department of Health & Human Services (DHHS) - (1) Administration on Community Living (ACL) – Administration on Intellectual Developmental Disabilities (AIDD); and (2) Centers for Medicare & Medicaid Services (CMS) -Incentive Grants (Awards for deinstitutionalization/ Deflection from Long Term Care Facilities)
Funding Involved	No funding is requested; Bill Language is requested

#### TESTIMONY

Chairman Cole, Ranking Member DeLauro, and Members of the Committee, thank you for the opportunity to provide testimony on the FY 2016 Budget for the Department of Health and Human Services (DHHS).

My work as an advocate for vulnerable persons who cannot care for themselves started for one simple reason: my son with severe disabilities.

I am Carole Sherman, of Arkansas, the mother and co-guardian of John, aged 46, who from birth has lived with the effects of severe brain injuries. Our son is a large, mobile and nonverbal man with pica behaviors (eating inedibles), who functions on the mental level of a young toddler - a two-year old, to be more exact. John has slight or little awareness of danger and for many years his safe home has been a state-operated, Medicaid certified congregate care program.

I represent as public affairs chairman Families and Friends of Care Facility Residents (FF/CFR), Arkansas' statewide parent-guardian association. FF/CFR is an all-volunteer organization; we employ no lobbyist; we receive no public funds. In behalf of our families and our family members with disabilities, I ask for relief from the programs within Department of Health and Human Services (DHHS) which commit taxpayer funds for activities which undermine and eliminate long-term care facilities for persons who cannot care for themselves.

I have reviewed the written and oral testimonies of Secretary Sylvia Burwell, who represented DHHS before the subcommittee on February 25, 2015. Her testimonies do not describe our families' experiences with the Department. I did not find descriptions of the actions and goals of (1) DHHS/Administration on Community Living (ACL) - Administration on Intellectual Developmental Disabilities (AIDD); and (2) Centers for Medicare & Medicaid Services (CMS) - Incentive Grants to achieve the deinstitutionalization of defenseless persons from their safe congregate care homes and the deflection from long term care facilities of qualified individuals. I did not find a description of DHHS incentive grants offered to states if they will shift from caring for persons in institutional settings to providing care in "community" settings. I did not find a description of the policies which permit programs within DHHS/Administration on Community Living (ACL) to bring federal lawsuits and threaten



federal lawsuits, to lobby against congregate care programs in the misguided goals of downsizing and eliminating congregate care facilities for persons unable to care for themselves.

In her testimony before the subcommittee, Secretary Burwell requested funding for the following activities: (1) Providing all Americans with Access to Quality, Affordable Health Care; (2) Delivering Better Care and Spending our Health Care Dollars Wisely; (3) Leading the World in Science and Innovation; (4) Ensuring the Building Blocks for Success at Every Stage of Life; (5) Keeping Americans Healthy; and (6) Leaving the Department Stronger.

The general public would agree that the goals and activities listed are an appropriate use of taxpayer funds by DHHS. I submit that the general public would not agree that the Department should use public funds to offer the states an increase in federal Medicaid funds to shift from providing care for vulnerable persons in licensed facilities to providing care for vulnerable persons in “community-settings” (child or adult foster care or supported living arrangements or group homes). To favor the model of “community care,” which has less oversight and monitoring requirements, over the model of licensed-facility based care for persons who cannot report their hurts and needs and who cannot care for themselves is dangerous and is wrong. Examples of DHHS-Centers for Medicare and Medicaid (CMS) financial incentive grants which reward states by their shifting from the model of licensed care are: Balancing Incentive Program (2% increase), Money Follows the Person (up to 90% of 1<sup>st</sup> year’s cost, plus generous one-time transition funds), Community First Choice (6% increase).

I submit that the general public would not agree that the Department should use public funds to bring legal actions (or the threat of legal actions) against states’ public safety net programs for vulnerable persons. In support of its deinstitutionalization work, DHHS-ACL-AIDD has adopted an incomplete and partisan interpretation of the Americans with Disabilities

Act (ADA) and of the U.S. Supreme Court decision in the case identified as “*Olmstead*” (*Olmstead v. L.C.*, 119 S. Ct. 2185, 2187 (1999)). DHHS-ACL-AIDD ignores the portions of *Olmstead* which support the option of institutional care. Actions by programs administered by DHHS-ACL-AIDD have resulted in the closures of congregate care programs for persons who are severely disabled, those who cannot care for themselves. DHHS-ACL ignores the objections of families to AIDD programs’ actions; DHHS has turned a blind eye to the tragic consequences for many vulnerable persons when they have been moved from their safe Medicaid-certified congregate care homes. DHHS fails to include all stakeholders in its policy-making decisions. There is a lack of transparency in the Department’s goals for the nation’s population with cognitive deficits/developmental disabilities.

At the February 26, 2015 LHHSE subcommittee hearing, Congressman Steve Womack asked DHHS-ACL Commissioner Kathy Greenlee about the activities of ACL-AIDD programs. He asked if it was the goal of the agency to eliminate long-term care facilities for persons who cannot care for themselves. (<https://www.youtube.com/watch?v=Yy4Dtycyg9o> - Congressman Womack’s line of questioning is at the 1:32:15 mark). Commissioner Greenlee stated “We are not a facility-closure agency.” It does not seem possible that the administrator of ACL-AIDD could be unaware of how the AIDD programs work in the states (and of how their national organizations’ work in the Congress) to undermine and eliminate long-term care facilities for persons with cognitive-developmental disabilities.

**Requests:** (1) Please bring to an end DHHS financial incentive grants which favor “community-settings” over “congregate care settings.” (2) Please bring an end to DHHS-ACL-AIDD programs’ which work to undermine and eliminate long-term care facilities for people who cannot care for themselves.

**Proposed Bill Language:**

(1) Federal agencies may not commit federal funds to reward states financially to shift from providing care to vulnerable persons in licensed facilities to providing care to vulnerable persons in community - only settings.

(2) Federal agencies may not commit federal funds: (a) to bring a lawsuit against a public or private long-term care facility whose residents are unable to care for themselves when the targeted facility is in compliance with the regulations of its funding authority; (b) to bring a lawsuit against a public or private long-term care facility for persons who cannot care for themselves when no resident, or member of a resident's family or Court- fairly authorized representative, e.g., a guardian, has joined in the lawsuit's claims; (c) to bring a lawsuit against a public or private long-term care facility for persons who cannot care for themselves when facility residents do not have the option to opt out of the lawsuit; or (d) to bring a lawsuit against a public or private long-term care facility for persons who cannot care for themselves when quality of care is not the issue.

**Proposed Report Language:**

The Committee notes that the 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* does not mandate deinstitutionalization: "We emphasize that nothing in the Americans with Disabilities Act (ADA) or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead v. L.C.*, 119 S. Ct. 2185, 2187 (1999).

Submitted via email to: [LH.Approp@mail.house.gov](mailto:LH.Approp@mail.house.gov)

April 29, 2015

Dear Chairman Cole and Ranking Member DeLauro:

My name is James P. Bergeron, and I am the President of the National Council of Higher Education Resources (NCHER), a trade association that represents higher education service agencies, including loan servicers, that assist students and families access, manage, and pay for the costs of postsecondary education. NCHER urges the Subcommittee to provide \$855.211 million for the U.S. Department of Education's Student Loan Servicing activities in the Fiscal Year 2016 Labor, Health and Human Services, Education, & Related Agencies Appropriations Act. This amount is \$133.511 million over last year's funding level, and is necessary due to increased volume under the William D. Ford Direct Loan Program and the renegotiated pricing for federal student loan servicing contracts.

As you know, as of October 1, 2014, Federal Student Aid's portfolio of student loans includes nearly 30 million student and parent borrowers. Over the last two years, outstanding Direct Loan volume has increased from \$694 billion to \$787 billion, and is expected to increase to \$877 billion in 2016. New student loan volume has increased from \$101.749 billion in 2014 to \$103.915 billion in 2015, and is estimated to increase to \$109.160 billion in 2016. In academic year 2013-2014, federal student loans accounted for about 59 percent of all federal student aid.

Since 2009, the Department of Education has used Not-for-Profit (NFP) Servicers, in addition to the original four Title IV Additional Servicers (TIVAS), to provide important services to student and parent borrowers with loans made under the Federal Direct Loan Program. The nation's student loan servicers provide an array of important, high-quality services to student and parent borrowers, at minimal costs to the federal government. Besides handling general billing and payment processing, student loan servicers:

- Are the primary point of contact for borrowers to answer questions about their student loans and repayment options. For students that are in-school or in their 6-month grace period before beginning repayment, the servicer may be their first contact with anyone who helps them with their loan. Student loan servicers spend millions of dollars locating, contacting, and educating students on their financial obligations and how to balance their student loan payments with other bills.
- Assist students and parents that are in repayment on their student loans, including working with these borrowers to identify and enroll in the most appropriate repayment and loan consolidation plans to meet their unique and individual financial situation.
- Assist servicemen and women in understanding and signing-up for the benefits under the Servicemembers Civil Relief Act (SCRA). Each servicer has a dedicated person with expertise who has been specially trained to respond to inquiries on all aspects of the military entitlements, forms, regulations, and military repayment options as they relate

to federal financial aid. All student loan servicers review the borrowers in their portfolio against the U.S. Department of Defense (DOD) database monthly and apply the benefit based on that match.

- Help borrowers who are delinquent in repaying their loans, including ensuring they are aware of the various options under the law to get their student loans back in good standing.
- Assist students in identifying and receiving all benefits associated with their student loans, including programs that provide forgiveness for borrowers pursuing careers in public service and for borrowers who qualify for loan discharge due to closed schools or due to death and disability.

Student loan borrowers and the American public expect high-quality service from the nation's student loan servicers. To ensure this high standard is met, adequate federal resources must be available to support these important labor and technology intensive functions consistent with the contract requirements entered into by the federal servicers and the Department of Education. For example, the Department's new pricing and performance metrics provide a greater emphasis on servicing those accounts that are in repayment, which requires significant and multiple interactions with student and parent borrowers, including the tasks associated with due diligence in loan collections. These efforts are especially expensive when working with borrowers that are delinquent on their student loan payments.

According to data released by the Institute for Higher Education Policy, approximately 58 percent of all student loans (\$543.3 billion) are in repayment with the remaining percentages in deferment, forbearance, grace, or default. Of this total:

- \$23.4 billion is attributable to borrowers who are 31 to 90 days delinquent in paying their loans.
- \$13.4 billion is attributable to borrowers who are 91 to 180 days delinquent.
- \$8.6 billion is attributable to borrowers who are 181-270 days delinquent.
- \$4.5 billion is attributable to borrowers who are 271-360 days delinquent.

These figures are echoed in a recent Federal Reserve Bank of St. Louis study that estimates that nearly a third of all borrowers in repayment are more than 30 days delinquent on their federal student loan payments. The additional federal funding will allow the federal student loan servicers to tackle this growing problem.

Under the terms of the Consolidated Appropriations Act, 2014, the Department is required to move towards the establishment of comparable portfolios between the Title IV Additional Servicers (TIVAS) and NFP Servicers, primarily by assigning new loans through the Common Origination and Disbursement (COD) system. The Department began assigning new volume to the NFP Servicers in January 2015, instituted a new pricing and performance structure, and anticipates beginning the overall procurement process for re-competition of contracts later this year. A competitive contracting structure promotes high levels of customer

service, protects the interests of the federal government while providing important services to borrowers, encourages innovation, and saves taxpayers money. However, the competitive structure envisioned by Congress requires the establishment of comparable portfolios.

NCHER strongly supports opportunities for the NFP Servicers to receive additional loan volume before the upcoming re-competition. NFP Servicers have a strong and proven record of helping students, families, and borrowers repay their student loans. All of the existing servicers have invested significant time and resources, including substantial compliance costs to become federal contractors, to be able to service federally-held student loans. This investment was undertaken with the bipartisan and bicameral encouragement of Congress and the Department. The Committee should support the efforts of high-performing servicers to receive additional loan volume through the upcoming Labor/HHS/ED Appropriations Act.

NCHER appreciates the opportunity to provide feedback on its funding priorities. We look forward to working with members of the Subcommittee as it drafts the Labor/HHS/ED Appropriations Bill to ensure that students and families continue to receive high-quality services throughout their postsecondary education career.

Thank you.





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Testimony of

**Phil Mulder, PhD, President**

**Entomological Society of America**

On

**Fiscal Year 2016 Appropriations for the National Institutes of Health and Centers for**

**Disease Control and Prevention**

Submitted to the

**Appropriations Subcommittee on Labor, Health and Human Services, Education, and**

**Related Agencies**

**United States House of Representatives**

April 29, 2015

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for insect-borne disease research at the U.S. Department of Health and Human Services (HHS). **ESA requests a robust fiscal year (FY) 2016 appropriation for the National Institutes of Health (NIH), including the President's proposed increase in funding for insect-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports the President's increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) in order to fund scientific activities related to vector-borne diseases.**

Advances in the biological sciences, including the field of entomology, help to address some of our most pressing societal needs related to environmental and human health. Certain species of insects carry, spread, and transmit an array of infectious diseases that threaten populations across the globe, including those in the United States as well as U.S. military personnel undertaking missions abroad. Insect-borne diseases can present an especially challenging health problem; few vaccines have been developed against them, and insects are often difficult to control and can develop resistance to insecticides. The risk of emerging infectious diseases grows as global travel becomes easier and environmental factors continue to change. For example, West Nile virus, which is transmitted by mosquitoes and was not present in the U.S. before 1999, infected 5,674 Americans in 2012.<sup>1</sup> Entomological research to understand the biological relationship between insect vectors and the infectious diseases they carry – such as dengue, malaria, West Nile virus, and Lyme disease – can significantly contribute to our ability to monitor and predict outbreaks, prevent disease spread and transmission, and more reliably diagnose and treat infection. **Given the important role that insect vectors play in impacting human health, ESA urges the subcommittee to support vector-borne disease research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.**

NIH, the nation's premier medical research agency, advances human health by funding research on basic human biology and disease and the development of prevention and treatment strategies. More than 80 percent of NIH funding is competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the nation. As one of

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<sup>1</sup> CDC's Division of Vector-Borne Diseases Factsheet, [http://www.cdc.gov/ncezid/dvbd/pdf/dvbd\\_factsheet.pdf](http://www.cdc.gov/ncezid/dvbd/pdf/dvbd_factsheet.pdf).

NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious, immunologic, and allergic diseases. One example of NIAID-funded research on infectious diseases is a study examining the mechanism by which certain species of mosquitoes known to transmit dengue and malaria are attracted to humans. The scientists discovered that specific types of nerve cells in the insects act as sensitive detectors of human odors. With this knowledge, the researchers were able to identify safe and natural chemical compounds with the potential to neutralize or overwhelm the specific insect nerve cells, a discovery that could have implications for the control of mosquitoes and their associated diseases.<sup>2</sup> In another recent study supported by NIAID, researchers determined that live, disease-free ticks can be used as a safe tool for testing for the presence of Lyme disease bacteria in patients who have completed antibiotic therapy.<sup>3</sup> Lastly, the President's FY 2016 budget request also spotlights advancements made in chikungunya research. Specifically, research supported by NIAID developed "a genetically engineered, live-attenuated chikungunya vaccine that protected non-human primates with a single dose and may also interrupt viral transmission in mosquitoes."<sup>4</sup> **To ensure funding for future groundbreaking projects like these, ESA supports increased funding for NIAID and encourages the committee to support insect-borne disease research at NIH. In particular, ESA supports**

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<sup>2</sup> Tauxe, GM, et al. *Targeting a dual detector of skin and CO2 to modify mosquito host seeking*. Cell (2013).

<sup>3</sup> Marques, A, et al. *Xenodiagnosis to detect Borrelia burgdorferi infection: A first-in-human study*. Clinical Infectious Diseases (2014).

<sup>4</sup> NIAID Budget Justification, FY 2016, <http://www.niaid.nih.gov/about/Documents/FY2016CJ.pdf>

**the President's requested increase of \$94,508 million above the FY 2015 enacted level for Biodefense and Emerging Infectious Diseases.**

CDC, serving as the nation's health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, whether naturally arising or related to bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) seeks to protect our nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology. For example, among the activities supported by DVBD are the ArboNET surveillance system for mosquito-borne diseases, the TickNET system for tick-borne diseases, and Puerto Rico's new SaludBoricua self-reporting system that was recently expanded to include the public. ArboNET is a nationwide network that monitors West Nile virus and other diseases through activities such as the collection and testing of mosquitoes, and TickNET is a partnership between 16 states to track tick-borne-diseases like Lyme disease and test preventions. The new SaludBoricua system will help to monitor vector-borne diseases like dengue, influenza, and chikungunya in Puerto Rico. Furthermore, a component of CDC's global health budget supports activities on parasitic diseases and malaria; this includes the maintenance of a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission.

Specifically within the President's CDC Budget Request for FY 2016, there was a proposed increase of \$275.562 million for Core Infectious Diseases over the FY 2015 enacted level, which includes the vector-borne diseases program. The CDC FY 2016 budget justification also highlights the chikungunya virus, along with several other vector-borne diseases like dengue,

West Nile virus, and Lyme disease, as vector-borne diseases program priorities. Regarding chikungunya, the justification stated, “By December 2014, a million suspect and confirmed cases had been reported from 42 countries throughout the Caribbean and South, Central, and North Americas. In addition, almost 2,000 cases have been reported in Puerto Rico, the U.S. Virgin Islands, and American Samoa. Eleven locally-acquired cases of chikungunya have been detected in Florida and over 2,000 travel-associated cases have been identified from 46 states.”<sup>5</sup> ESA is pleased to see that chikungunya and other insect-borne diseases are an upcoming FY 2016 priority for CDC and encourages the inclusion of entomological sciences in future research addressing these diseases. **Given the important contributions of CDC, ESA requests that the committee provide the President’s requested increased support for CDC programs addressing vector-borne diseases and malaria.**

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America’s support for HHS research programs. For more information about the Entomological Society of America, please see <http://www.entsoc.org/>.

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<sup>5</sup> Center for Disease Control and Prevention Justification of Estimates for Appropriation Committees, FY 2016, [http://www.cdc.gov/lmo/topic/Budget%20Information/appropriations\\_budget\\_form.pdf/FY2016\\_CDC\\_CJ\\_FINAL.pdf](http://www.cdc.gov/lmo/topic/Budget%20Information/appropriations_budget_form.pdf/FY2016_CDC_CJ_FINAL.pdf)

U.S. Senate Appropriations Subcommittee on Labor, HHS, Education and Related Agencies FY2016 -- Version for the Hearing Record  
 Daniel Paul Perez, FSH Society on facioscapulohumeral muscular dystrophy. 29 April 2015

Testimony of Daniel Paul Perez, President & CEO, e-mail: [daniel.perez@fshsociety.org](mailto:daniel.perez@fshsociety.org)  
 FSH Society, 450 Bedford Street, Lexington, MA 02420, phone: (781) 275-7781, before the  
 United States House Appropriations Committee, Subcommittee on Labor, Health and Human  
 Services, Education and Related Agencies on the subject of **\$21 million in FY2016**  
 Appropriations for U.S. DHHS National Institutes of Health **NIH** Research Programs on  
**Facioscapulohumeral Muscular dystrophy (FSHD)** April 29, 2015

*Agency: National Institutes of Health (NIH).*

*Account: NINDS, NIAMS, NICHD, NHLBI, NHGRI and others as appropriate.*

***Suggested FY 2016 Report Language:** The Committee encourages the NIH to foster opportunities for multidisciplinary research on facioscapulohumeral muscular dystrophy (FSHD), a common and complex form of muscular dystrophy, commensurate with its prevalence and disease burden. The Committee hopes such advances will be utilized to help advance treatments and access to therapies for this grave disease.*

Honorable Chairman Cole and Ranking Member DeLauro, thank you for the opportunity to submit this testimony. Facioscapulohumeral muscular dystrophy (FSHD) may be the most common muscular dystrophy with a prevalence of 1:8,000.<sup>1</sup> For approximately 870,000 men, women, and children worldwide the major consequence of inheriting this condition may be a lifelong progressive loss of all skeletal muscles. The National Institutes of Health (NIH) is the principal source of funding of research on FSHD currently at the \$7 million level. I am pleased to report that your help and investment has produced remarkable scientific returns.

**1. Congress has made a major difference.** I have testified approximately fifty times. When I first testified, we did not know the genetic mechanism of this disease. Now we do. Now we can target it. When I first testified, FSHD was considered rare; now it may be the most prevalent form of muscle disease. Congress is responsible for this success, through its sustaining support of the NIH and the enactment of the Muscular Dystrophy CARE Act. We are aware that MD Care Act does not set the amount of spending on FSHD or the other dystrophies at the NIH and we recognize that funding levels are determined in the appropriations process and the numbers of grant applications received and funded by the NIH on FSHD. With this understanding, we are requesting that Congressional appropriations ask NIH to seize on great

opportunities to advance treatments for FSHD that will not require increasing the NIH budget, nor diminish other research while gaining more efficiency out of a non-growing research budget.

**2. Quantum leaps in our understanding of FSHD.** The past four and a half years have seen remarkable contributions made by a very small but extremely dedicated tribe of researchers funded by NIH and non-profits.

#### TABLE 1

- On August 19, 2010, American and Dutch researchers published a paper which dramatically expanded our understanding of the mechanism of FSHD.<sup>2</sup> A front page story in the *New York Times* quoted the **NIH Director Dr. Francis Collins** saying, "If we were thinking of a collection of the genome's greatest hits, this would go on the list."<sup>3</sup>
- Two months later, another paper was published that made a second critical advance in determining the cause of FSHD. The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.<sup>4</sup>
- On January 17, 2012, an international team of researchers based out of Seattle discovered a stabilized form of a normally suppressed gene called DUX4 affects many different germline genes, retro-elements, and immune mediators: all potential targets.<sup>5</sup>
- Six months later, another high profile paper produced by a Senator Paul A. Wellstone Muscular Dystrophy Cooperative Research Center of the NIH (mandated by MD CARE Act), used sufficiently "powered" large collections of genetically matched FSHD cell lines generated by the NIH center that are both unique in scope and shared with all researchers worldwide, to improve on the Seattle group's finding by postulating that DUX4-fl (full-length) expression is necessary but not sufficient by itself for FSHD muscle pathology.<sup>6</sup>
- On July 13, 2012, a team of researchers from the United States, Netherlands and France identified mutations in a gene called SMC1D1 causing 85% of another form of FSHD called FSHD1B or FSHD2. This paper furthers our understanding of the molecular pathophysiology of FSHD. This work too was supported in part by a program project grant from NIH.<sup>7</sup>
- On September 25, 2014, researchers from United States, France, Spain, Netherlands and United Kingdom narrow the focus mechanistically opening the possibility of all types of FSHD having an epigenetic basis.<sup>8</sup>
- On March 29, 2015, different researchers involved with the NIH Senator Paul A. Wellstone Cooperative Research Center using its large collection of different FSHD patient samples and different techniques arrive at the same answer that there is an underlying principle of epigenetics defining asymptomatic or non-manifesting and playing a role in disease severity.<sup>9</sup>

Many of these findings have their origins in seed funding from the FSH Society to researchers who have then used preliminary data to secure funding from the NIH. In simpler terms, our own genes within us are being inappropriately expressed in muscle tissue at a time and place where they do not normally reside or function by a confluence of events in a variety of ways giving rise to the decay and destruction of skeletal muscle; and we begin to focus on the very narrow stretch of DNA down to the nucleotide level in an area adjacent to the toxic gene inappropriately turned on so-named DUX4-fl (full-length). Think of it as the opposite of cancer rather than runaway genes causing unbridled cell growth; runaway genes are causing unbridled cell death. What is fascinating is, though one has all the requisites to have FSHD (e.g. the presence of a

chromosome 4qA containing a DUX4 polyadenylation signal; and either a truncation of D4Z4; or a SMCHD1 mutation with D4Z4 repeat array with array sizes at the lower end of the normal repeat size spectrum) there are modifiers that allow a person to have symptoms of FSH disease whilst other genetically tested positive relatives are spared of disease symptoms e.g. methylation and modifiers. We can see clearly now that the stability of epigenetic repression by the region just upstream of DUX4 gene on the very last distal D4Z4 repeat, regardless of which route DUX4-fl was stabilized and presented FSHD1, FSHD2, FSHD3, etc., is a key regulator that can be modified perhaps via its methylation level/status. FSHD2 modifies FSHD1 in individuals who carry both mutations presenting even more severe disease. Even more remarkably, we have compounds and techniques to modify and target modifiers and expression of DUX-fl, and still the FSHD research and clinical enterprise is starved for federal funding from NIH! In 2014, the FSH Society funded projects to silence the DUX4 gene using leading-edge genome-editing technologies (CRSPR/Cas, TALEN), helped support efforts in development efforts and models to test anti-sense oligonucleotide (ASO) and morpholino and we aided the development of animal models and a novel method that we believe will revolutionize FSHD diagnostics. We are thrilled that our grantees and colleagues have data that proves that DUX4-fl and cascading events can be turned off.

**3. We must keep moving forward.** In October 2014 the FSH Society held its annual FSHD International Research Consortium meeting. The meeting was funded in part by the NIH NICHD University of Massachusetts Medical School Wellstone center for FSHD. Nearly 85 researchers gathered to present latest data and discuss research strategies. The discussion agenda focused on being prepared for intervention development and clinical readiness. To keep focused we followed the path: Genetics > Mechanisms and targets > Models > Patients. The priorities



stated for 2015, at the October 18, 2014, FSH Society FSHD IRC meetings can be found at:

<http://www.fshsociety.org/international-research-consortium/>

Additionally, on March 17th, 2015, the FSH Society presented to the MDCC its concern about the small number of NIH grants and that much greater funding is required to address the most pressing challenges for FSHD research, including research on topics listed in Table 2.

**TABLE 2**

- Mechanisms of DUX4 toxicity
- More molecular, imaging and functional markers of disease progression
- Modifiers of disease: genetic, chemical, and lifestyle
- Preclinical models validated to represent aspects of FSHD pathophysiology
- Better animal models based on low expression of DUX4 as seen in patients
- Mechanisms of pathology in patients' muscles
- Normal functions of DUX4 in tissues other than muscle
- Methods of administering anti-DUX4 agents to muscle
- Muscle regeneration capacity in FSHD muscles
- Large animal models (monkey, marmoset)
- Biomarkers that can indicate impact of therapeutic agents.

**4. NIH Funding for Muscular Dystrophy.** Mr. Chairman, since Congress passed the MD CARE Act in 2001, research funding at NIH for muscular dystrophy has increased 4-fold from \$21 million. While FSHD funding has increased 14-fold from \$500,000 during this period. The FSHD funding level at the NIH has been basically flat for the past seven years.

**FSHD Research Dollars (in millions) & FSHD as a Percentage of Total NIH Muscular Dystrophy Funding**  
Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e = estimate)

Fiscal Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015e	2016e
All MD (\$ millions)	\$38.7	\$39.5	\$39.9	\$47.2	\$56	\$83	\$86	\$75	\$75	\$76	\$78	\$79	\$81
FSHD (\$ millions)	\$2.2	\$2.0	\$1.7	\$3	\$3	\$5	\$6	\$6	\$5	\$5	\$7	\$7	\$7
FSHD (% total MD)	6%	5%	4%	5%	5%	6%	7%	8%	7%	7%	9%	9%	9%

We have communicated to the NIH leadership and the Muscular Dystrophy Coordinating Committee (MDCC) federal advisory committee mandated by the MD CARE Act our grave concern that FSHD research is way too under-represented and needs a proactive effort on the part of NIH. At the March 17, 2015, MDCC meeting we re-iterated to Alan E. Guttmacher, MD., Director, NICHD and Chair of the MDCC and all MDCC members that we are fully supportive of the Action Plan for Muscular Dystrophy; while at the same time we requested that NIH redress the imbalance of

funding in the muscular dystrophy portfolio with respect to FSHD. The NIH should address this issue head-on. In the last year alone, incredible opportunities for public, private and non-profit entities engaged in FSHD research and clinical research have emerged. Oddly these discoveries clearly belonging to the leading edge of human genetics and our understanding the epigenome and treating epigenetic diseases are sitting idle at NIH. NIH needs to see through the thick fog of fiscal distress and recognize that opportunities for the development of effective treatments for FSHD and epigenetic diseases have never been greater. While all muscular dystrophy research funding at NIH increased by \$41 million (\$39.9M 2006 to \$81M 2016e); FSHD increased by \$5.3 million (\$1.7M to \$7M). There is a real paradox in FSHD's order of magnitude difference in growth, being equally devastating and burdensome as the disease receiving the most funding in this category called muscular dystrophy, and though it functions in the exact same U.S. federal research infrastructure. **We request for FY2016, an NIH FSHD research portfolio of \$21 million correlating to 25% of the current estimated muscular dystrophy funding at NIH.** NIH can convey to researchers that it has a specific interest in FSHD. There are no quotas on peer-reviewed research above pay line at the NIH, and NIH can help. This is the time to fully and expeditiously exploit the advances in scientific opportunities for which the American taxpayer has paid. Thank you for this opportunity to testify before your committee.

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**Written Testimony for the Record of Edward A. Carraway  
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Submitted to the Senate Appropriations Subcommittee on Labor, Health & Human  
Services, Education and Related Agencies**

Subcommittee lawmakers have the chance to do right by some of our Country's most vulnerable citizens by prohibiting federally funded HHS agencies from using those federal dollars to close Medicaid facilities ("ICFs") serving people with intellectual disabilities. We acknowledge that it is not an easy choice, but it is the right choice.

We argue that forced "deinstitutionalization" activities are contrary to federal law and cause human harm, resulting in many documented cases, as provided below, with doubled, tripled and quadrupled mortality rates. And for those who remain as a facility is being closed often the services are not as best practices demand.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of federal funding.

Often citing the U.S. Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

Justice Kennedy noted in his concurring opinion, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191. "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's Amici Curiae brief]." *Id.*

As Justice Kennedys concurring opinion is quite clear, as to Choice of Residential Services and the best support systems which addresses each individual's quality of life issues and continuity of care and in compliance with the ADA, Federal Medicaid Act and Developmental Disabilities Assistance and Bill of Rights Act.

For years many states have not allowed new residents family or guardian to choose Public ICF's as they do not advertise this choice as a right to choose, and the availability thereof, as all public ICF's have vacancies. For instance the State of Florida has been guilty of this for years, and without public hearings or notice to families or guardian immediately, starts transitioning to community facilities without transition compatibility trials, and often with

substandard care and qualified professionals available as to needs and timing of its availability.

Often Emergency rooms become a replacement for services by public ICFs.

Here are some examples of the recent past.

An audit provided by my home state Florida, who returned over \$80,000,000 to the Treasury last year, where the statistics spread sheet provided has 20,940 individuals with syndromes, conditions, and challengers on the wait list and more than 1300 of those with intensive needs on a wait list who would qualify for public ICFs if family were made aware of such. A few years ago they returned almost \$100,000,000 designated. And many families would like to place their family member in a public ICF as it decreases the chances of them becoming “couch potatoes” as such have recreational facilities, Special Olympics, worship facilities, swimming and therapeutic pools, daily therapists, counselors, prescriptions available, medical staff on duty 24/7, most of all Dentistry, hobby shops, training job skills, with support and participation of many organizations in the community. And facilities designed for the residents to safely walk and roam with security provided 24/7. And equipped to work with all phases of life from pediatric to hospice stage with licensed and trained staff as required by those with DD/ID/MI dual diagnosed. These are very limited in group homes as individuals must be transported to doctors and/or emergency rooms at great cost to their care. For some, emergency rooms can become their care provider due to timing and urgency and limited number of doctors who accept Medicaid and geographical desirability.

### **Mortality media report on deaths after Deinstitutionalization.**

ARC Attorney in Pennsylvania posits a few tragedies are the price of progress”.... so *what if a few people died being transferred from larger settings to smaller ones....*

INDIANA: Parents told to drop disabled kids at shelters; State budget cuts have left families with no affordable care options

Summary: The Arc of Indiana's website boasts that Indiana is the. “largest state without state institutions for people with developmental disabilities”. The article below reports that the waiting list of home and community based waiver services exceeds 10,000 people, with some families waiting for 10 years for service, and additional service cuts predicted as a result of budget deficits. As a result, some families desperate for services have been referred to homeless shelters. 10,000 + people on a waiting list, no public ICFs/MR, and homeless shelters. The connection seems clear.

KENTUCKY: Organization sues for access to records of individual who died following community setting Kentucky's Council on Developmental Disabilities (NOT the state's DD Council) filed a lawsuit against the Cabinet for Health and Family Services August 19 for denying access to records for an individual with developmental disabilities who died after being transitioned to a community placement. What do they have to hide?

NEBRASKA: 10 deaths--nine months.

Nebraska Radio Report November 2009. In nine months a 10th person has died from among 47 "medically fragile" residents, an alarming rate of almost one out of five who were moved from Beatrice State Development Center last February. Residents and Families were given very little notice. Residents who were transferred have filed a lawsuit.

#### VIRGINIA: Community placement doubles mortality rate

*News and Advance (Lynchburg, VA) \* March 11, 2015*

In her March 1 letter to the editor, Commissioner Debra Ferguson, of the Department of Behavioral Health and Developmental Services, stated, "Safety and care of those with intellectual disabilities are our paramount concerns", yet the schedule for training center closures and the actions of the department she leads indicate otherwise.

Data provided by the department last fall to the Virginia Senate work group and posted on its website were sufficient for me to perform an analysis comparing the mortality rate of those who have left training centers with a similar population of those who remained. My analysis showed that the mortality rate of those who left was double that of those who stayed. Meanwhile, discharges progress without hesitation.

Again; Subcommittee lawmakers have the chance to do right by some of our Country's most vulnerable citizens by prohibiting federally funded HHIS agencies from using those federal dollars to close Medicaid facilities ("ICFs") serving people with intellectual disabilities. We acknowledge that it is not an easy choice, but it is the right choice.



Submitted by: Robert J. Beall, Ph. D., President and Chief Executive Officer

On behalf of the Cystic Fibrosis Foundation (CFF) and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the House Committee on Appropriations' Subcommittee on Labor, Health and Human Services, Education and Related Agencies requesting at least \$32 billion for the National Institutes of Health (NIH) for fiscal year 2016. We also encourage special consideration and support for the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction as well as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung, and Blood Institute (NHLBI), which play a vital role in CF research.

We also recommend that the Committee provide robust resources to the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), particularly their work to support nationwide newborn screening programs. Further, we urge the provision of ample funding for the Center for Medicare and Medicaid Innovation (CMMI) to allow this agency the resources needed to update and streamline payment systems from the traditional fee for service model.

**Cuts to Funding Impede American Research and the Economy** - NIH uses appropriated funds wisely and effectively to promote basic research and encourage collaboration across sectors to develop the building blocks of drug development. Basic research is a vital prerequisite for the discovery of new treatments and cures, and the level to which NIH funding has been diminished is deeply troubling and detrimental to efforts to develop treatments for serious and life threatening diseases.

According to the Journal of the American Medical Association, the NIH budget declined nearly 2 percent per year after the mid 2000's, totaling in a full 13 percent decrease in NIH purchasing power since 2004. This has had devastating and lasting effects on the state of American research labs both at the NIH



and in collaborative programs across the country. Success rates for all investigators continue to decline, and new investigators struggle to obtain enough funding to remain in the field.

Cuts to funding at the NIH have been detrimental to those seeking funding for CF research. Large Center Core Grants, awarded by the NIDDK, support shared resources and facilities for use by multiple investigators and provide much needed funding for clinical and basic cystic fibrosis research centers. As funding dwindles, competition for these grants increases, and large centers face the realities of losing their funding. This is detrimental to individual centers and causes interruption and uncertainty in CF research overall.

While NIH funding has been inadequate to fulfill the urgent need for basic research, work performed at the agency has had benefits for the U.S. economy, supporting more than 402,000 jobs and \$57 billion in economic output in 2012 according to United for Medical Research. Increased investment in NIH can provide even greater economic payoff and the scientific progress that makes the U.S. the worldwide leader in biomedical research.

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and in bringing together various stakeholders in order to streamline the research process.

NIH-funded advances like the mapping of the human genome and the development of high throughput screening were essential to the creation of Kalydeco™, a cystic fibrosis treatment approved in 2012. This breakthrough drug, developed by Vertex Pharmaceuticals with significant support from the CF Foundation, is the first to treat the underlying cause of CF in those with particular genetic mutations that impact about 8 percent of the CF population.

More exciting advancements are in the pipeline, as successful phase 3 clinical trials have been completed on a combination of Kalydeco and a new compound, VX-809. This combination would treat those with the most common CF mutation, comprising about 50 percent of those with CF in the United

States. A New Drug Application (NDA) has been submitted to the FDA for this treatment, and a decision is expected by July 5.

CFF also works with the NIH to fund and organize a number of research initiatives. This collaborative model allows for an efficient, well-funded research process. For example, the OPTIMIZE study, jointly funded by the NIH and the CF Foundation, has brought together hospital systems in nearly 30 states to compare the effectiveness of antibiotics treatments for lung infections in those with cystic fibrosis.

In addition, we urge support for the continuation and expansion of research networks, such as NIH's Childhood Liver Disease Research Network (ChILDRen) consortium at the NIDDK. This successful collaboration helps researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

The CF Foundation also urges the Committee to support collaborative efforts by the FDA and the NIH, such as the Regulatory Science Initiative and initiatives that allow for the placement of employees part-time at FDA and part-time at the NIH. Collaboration between the NIH and FDA can help move innovative new drugs more quickly through the development process to patients by ensuring that the NIH has the resources to support all aspects of the research process, including updated tools and technologies as well as adequate staff support.

**The Precision Medicine Initiative** - Please support the President's full funding request of \$215 million for the Precision Medicine Initiative to spearhead the research and development of therapies that treat the underlying genetic cause of different diseases.

This promising new frontier will likely necessitate changes in the structure of research being performed at the NIH. It is yet unclear if the Precision Medicine Initiative will ultimately extend to all institutes housed by the agency or if it will be a supplemental focus of several select research groups. The Foundation urges the NIH to adopt precision medicine as a focus in a wide array of applicable areas, but

the undertaking of such a broad and powerful initiative is concerning given the current state of funding levels at the NIH.

The agency does not have enough support to undertake this vital initiative without drawing much needed resources from other research areas. As such, the Foundation strongly supports robust funding for this agency so that it can have the freedom it needs to promote the development of personalized therapies for serious, life threatening conditions like cystic fibrosis.

**Preparing for a New Era of Medicine** - Please provide adequate resources and support the work of CMMI, in order to encourage changing payment systems to reward greater quality and value of care, rather than the traditional fee for service system.

**Prioritizing a Centralized Institutional Review Board** - We commend the NIH for publishing and seeking comment on a policy that is intended to produce efficiencies in the clinical trials process while still protecting research participants by centralizing and simplifying the rigorous clinical trial review process.

NIH is the logical choice to lead the centralization of institutional review boards and requests that the committee take special consideration of the funds needed to implement this valuable initiative. At a time when research resources are restrained, efforts to reduce redundancy and improve efficiency in research are of the utmost importance.

**Advancing Translational Science at the NIH** - The Foundation requests increased funding for NCATS, which catalyzes innovation by improving the diagnostics and therapeutics development process and removing obstacles to translating basic scientific research into treatments to make translational science more efficient, less expensive, and less risky.

Specific programs housed in NCATS are integral to this mission, including the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN), and the Therapeutics for Rare and Neglected Diseases (TRND) program. They are designed to transform the way clinical and translational research is conducted and funded. NIH Director Dr. Francis Collins has cited the Cystic

Fibrosis Foundation's successful Therapeutics Development Network (TDN) as a model for TRND's innovative therapeutics development model.

**Clinical Trial Data Sharing** - We ask that Congress support efforts by the NIH to explore strategies and guidelines for clinical trial data sharing. As drug development research advances, data sharing is vital to the acceleration and efficiency of new discovery.

**Nationwide Newborn Screening Programs** - Newborn screening is critically important to the CF community because it allows for the early detection and treatment of disease symptoms as well as early use of CF corrector therapies, which can significantly reduce cumulative damage caused by the disease.

The Foundation urges the Committee to provide ample funding for HRSA, which evaluates the effectiveness of newborn screening and follow-up programs and provides grants for programs to improve newborn screening programs and other key functions.

We also request adequate funding to the CDC, which is responsible for strengthening and enhancing laboratory quality assurance programs, among other responsibilities.

**Conclusion** - Providing at least \$32 billion for the National Institutes of Health as well as robust funding for other relevant agencies will not only support and expand the important work already being done in biomedical programs and translational science but also encourage cost-efficient and effective collaboration of varied experts and stakeholders.

We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.



National Alliance on Mental Illness

**STATEMENT OF MARY GILIBERTI  
EXECUTIVE DIRECTOR, NATIONAL ALLIANCE ON MENTAL ILLNESS  
TO THE LABOR-HHS-EDUCATION SUBCOMMITTEE  
COMMITTEE ON APPROPRIATIONS  
U.S. HOUSE OF REPRESENTATIVES  
REGARDING FY 2016 FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL  
HEALTH (NIMH) AND THE SUBSTANCE ABUSE AND MENTAL HEALTH  
SERVICES ADMINISTRATION (SAMHSA)**

**APRIL 28, 2015**

Chairman Cole and members of the Subcommittee, I am Mary Giliberti, Executive Director of NAMI (the National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming FY 2016 bill. NAMI is the nation's largest grassroots advocacy organization representing persons living with serious mental illnesses and their families. Through our 1,100 affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with mental illnesses such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

An estimated 11.5 million American adults live with a seriously disabling mental illness, such as schizophrenia, bipolar disorder, and major depression. Based on estimates for 2010, mental disorders accounted for 21.3% of all years lived with disability in the United States. Among the top 20 causes of years lived with disability, five were mental disorders: major depressive disorder (8.3% of the total), anxiety disorders (5.1%), schizophrenia (2.2%), bipolar disorder (1.6%) and dysthymia (1.5%). Suicide is the 10th leading cause of death for adults in the US and the third leading cause of death for adolescents, accounting for the loss of more than 34,000 American lives each year, more than double the number of lives lost to homicide. The social and economic costs associated with these conditions are tremendous. A cautious estimate places the direct and indirect financial costs associated with mental illness in the U.S. at well over \$300 billion annually, and it ranks as the third most costly medical condition in terms of overall health care expenditure, behind only heart conditions and traumatic injury.

Judith Geisler, Director, Division of Formulary and Benefit Operations  
Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
Sent electronically to: [PartDFormularies@cms.hhs.gov](mailto:PartDFormularies@cms.hhs.gov)

**RE: Inclusion of All Approved Atypical Antipsychotic Medications in Plan Finder database**

Dear Ms. Geisler,

On behalf of the National Alliance on Mental Illness (NAMI), I am writing to address our concerns regarding the exclusion of certain dosages and formulations of atypical antipsychotics from the consumer and provider tool, Plan Finder on the Medicare.gov website. As the nation's largest organization representing people living with serious mental illness and their families,

NAMI urges you to address this current deficiency in this important tool and make efforts to ensure that all FDA-approved atypical antipsychotic medications are included in the Plan Finder tool.

Inclusion of all available FDA-approved atypical antipsychotic medications (e.g., dosages and formulations) is an important step in improving transparency of the Plan Finder drug database, as well as ensuring the tool is accurate based on available medications. Consumers, including Medicare beneficiaries living with mental illness as well as their caregivers and providers utilize tools like Plan Finder to help select the most appropriate plan offering for a Part D beneficiary. Since these beneficiaries may be treated with a variety of medications of different dosages and formulations throughout their journey, ensuring the information within Plan Finder is accurate is essential to ensure this as a reliable coverage tool.

To illustrate how the lack of consistency in Plan Finder listings could negatively impact individuals living with serious mental illness, the existing database allows an individual to select “Abilify Maintena” however, only the 300mg dose appears. The FDA-approved 400mg dose does not appear. For an individual trying to select a plan based on their specific prescribed medication, there is significant risk that they may draw an inappropriate conclusion that their 400mg dose of Abilify Maintena is not covered. This potentially inaccurate conclusion could lead to the individual selecting a less-optimal choice.

NAMI understands that CMS uses the existing Formulary Reference File (FRF), published by CMS, in part to drive the Plan Finder listings. While this is an available resource use for other purposes by plan sponsors, the FRF does not list all formulations and dosages for available products, therefore, this will inherently create an incomplete list of options. Since the purpose of Plan Finder is to provide a one-stop shop for consumers, caregivers and providers, it should follow that Plan Finder contain all available dosages and formulations for all products to ensure accurate decision-making.

NAMI urges CMS to recognize the importance of an accurate Plan Finder database that regularly includes updates to all available FDA-approved atypical antipsychotic medications for all of their dosages and formulations.

Thank you for your attention on this important issue for Medicare beneficiaries living with mental illness.

Moreover, these costs are not only financial, but also human in terms of lost productivity, lives lost to suicide and broken families. Investment in mental illness research and services are – in NAMI’s view – the highest priority for our nation and this Subcommittee.

### ***National Institute of Mental Health (NIMH) Research Funding***

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports a \$32 billion overall allocation for the National Institutes of Health (NIH). This increase is needed to prevent the United States from further falling behind China, India and other emerging nations in terms of investments in scientific research. As you know, the President is requesting a \$56 million increase for the National Institute for Mental Health (NIMH) for FY 2016, boosting funding for the agency to \$1.489 billion. NAMI urges the Subcommittee to fund investments beyond this amount with an overall higher allocation for the entire NIH.

NAMI also supports the President's BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) and the request for a \$70 million boost, up to \$135 million. The BRAIN Initiative is a multi-agency collaborative with a number of foundations designed to unleash new technologies and undertake basic mapping of circuits and neurons in the most complex organ in the human body.

### ***Supporting the NIMH 2015 Strategic Plan***

NAMI supports the new five-year NIMH Strategic Plan and its four overarching goals:

- Leveraging progress in genomics, imaging, and cognitive science to define the biology of complex behaviors,
- Building on the concept of mental disorders as neurodevelopmental disorders to chart trajectories and determine optimal times for interventions,
- Using discoveries to focus on new treatments (and eventually cures) based on precision medicine and moving trials into community settings, and
- Increasing the public health impact of NIMH research through improved services that improve access and quality of care.

### ***Accelerating the Pace of Psychiatric Drug Discovery***

In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect; failing to relieve symptoms in a significant proportion of patients; or, resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to identify quickly candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

### ***Advancing Services and Intervention Research***

NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH funded research is demonstrating progress advancing the health of people with serious mental illness. NIMH needs to advance this research to large-scale clinical trials aimed at reducing premature mortality with people living with serious mental illness.

### ***Investing in Early Psychosis Prediction and Prevention (EP3)***

As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illnesses such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays in seeking care—up to two years in some cases. Such delays result in periods of increased risk for adverse outcomes, including suicides, incarceration, homelessness and in a small number of cases, violence.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through the North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched the Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing promise in detecting risk states for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced FEP.

### ***Advancing Precision Medicine***

NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms. Through continued development, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

### ***Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)***

As noted above, the costs of untreated mental illness to our nation are enormous – as high as \$300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that across the nation states and localities devote enormous resources addressing the human and financial costs of untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of “spending money in all the wrong places” is tragic given that we have a vast array of proven evidence-based interventions that we know work such as assertive community treatment (ACT), supported employment, family psycho-education and supportive housing.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental illness. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the increases in funding for the MHBG that this Subcommittee has made in recent years, boosting funding from \$420 million in FY 2010, up to its current level of \$482.5 million in FY 2015. This increase has been important to helping states fill gaps in services that have occurred as states cut more than \$4 billion from state mental health budgets since the recession began in 2008.

NAMI also supports the 5% set aside in the in the MHBG that this Subcommittee enacted in FY 2014 for early intervention in psychosis, and opposes expansion to other at risk populations. As



noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment approach, combining evidence-based services into an effective, coordinated package. CSC emphasizes shared decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In 2014, CMHS issued guidance to the states specifying that funding as part of the 5% set aside must be used for those who have developed the symptoms of early serious mental illness, not for “preventive intervention for those at high risk of serious mental illness.” NAMI supports this guidance and we recommend that the Subcommittee continue this 5% set aside for FEP in FY 2016 and beyond. It is critically important for Congress to continue supporting the establishment of evidence-based FEP programs in all 50 states.

NAMI also recommends the following priorities for CMHS for FY 2016:

- Continuation of the Children’s Mental Health program at \$117 million,
- \$10 million in new funding in the President’s request for Crisis Systems, an initiative to support states and communities in developing mental health crisis-response systems with ongoing outpatient services and supports,
- A \$2 million increase for suicide prevention activities at CMHS, including funding for the Garrett Lee Smith Memorial Act.
- \$15 million in funding for states and localities as part of the Assisted Outpatient Treatment (AOT) pilot program as authorized by Congress in Section 224 of P.L. 113-93). We strongly believe that this funding should be used to study the effectiveness of a variety of approaches to engaging people with serious mental illness in treatment, including voluntary approaches for engaging people before they reach the point of requiring court-based interventions.

### ***Addressing Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care***

The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illnesses and substance use disorders are screened and treated at 126 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to reject the President’s proposal to cut this program by \$23 million in FY 2016 and fund the PBHCI at \$50 million.

### ***Addressing the Needs of Homeless Individuals Living with Serious Mental Illness***

On any given night, according to 2013 data, 610,042 people are homeless, and 15% of these individuals are defined as long-term or chronically homeless. Years of reliable data and research demonstrate that, for single individuals with complex needs due to serious mental illness, the most successful intervention for ending and preventing homelessness is linking housing to appropriate support services. Although there is a need for more affordable housing, funding the supportive services is even more difficult. SAMHSA homeless programs fill a gap created by a

preference of HUD to fund housing rental assistance and capital needs. HHS must take responsibility to fund the critically important services that are necessary for programs to be effective. Unfortunately, in 2014 SAMHSA was not able to award any new community-based services grants. The current FY 2015 funding level of SAMHSA homeless programs is \$74 million, divided between CMHS and CSAT. NAMI supports an increase for this joint program up to \$100 million, equally divided between CMHS and CSAT.

NAMI also supports funding for the PATH program (Projects for Assistance in Transition from Homelessness) that allocates funds by formula to states to serve homeless people with serious mental illness. Eligible services include outreach, screening and diagnosis, habilitation and rehabilitation, community mental health services, substance abuse treatment, case management, residential supervision, and housing. PATH supported programs reached over 192,000 people in FY 2014. Of these, 65% were unsheltered at the time of engagement, 42% were not engaged in mental illness treatment and 53% had co-occurring substance use disorders. NAMI recommends at least \$75 million for the PATH program for FY 2016 (the authorized amount). In FY 2015, the PATH program is funded at \$64.6 million.

### **Conclusion**

Chairman Cole, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's FY 2016 bill. NAMI's consumer and family membership thanks you for your leadership on these important national priorities.

April 28, 2015

Submitted for the Record

Leslie Ritter, Director of Government Affairs, Society for Women's Health Research (SWHR)

Before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and other Related Agencies

The Society for Women's Health Research (SWHR®) is pleased to have the opportunity to submit the following testimony to the Committee urging a renewed investment in scientific and medical research within the Department of Health and Human Services (HHS). For 25 years, SWHR has been widely considered the thought-leader in promoting research on biological differences in disease and we are dedicated to transforming women's health through science, advocacy, and education. We believe that Congress has a duty to appropriately fund a federal research agenda which is inclusive of women's health and sex differences research. **To accomplish this goal, we ask that the following agencies and programs be funded for fiscal year (FY) 2016 at the following levels:**

- **Agency for Healthcare and Research Quality (AHRQ)-\$479.3 million**
- **Centers for Disease Control and Prevention (CDC) -\$7.010 billion**
- **Health Resources Services Administration (HRSA)- \$10.4 billion**
- **National Institutes of Health (NIH)-\$32 billion**
- **Substance Abuse and Mental Health Services Administration (SAMHSA)-\$3.7 billion**
- **Office of Research on Women's Health at NIH (ORWH)-\$42 million**
- **HHS Office of Women's Health-\$41 million**

**Replace the BCA Spending Caps and Sequestration:** There is no question that one of the federal government's primary responsibilities is protecting the public health and investing in basic biomedical research to spur the way for the next generation of cures and therapies. Yet the spending caps set under the Budget Control Act (BCA) of 2011 and sequestration have resulted in massive cuts to non-defense discretionary programs (NDD). While reducing the federal deficit is important, SWHR remains deeply concerned with the extent of the cuts to NDD programs,

particularly those that impact public health and medical research agencies. We believe these policies should be replaced with a consistent and balanced approach to deficit reduction that places equal value on the roles of nondefense programs and defense programs in keeping Americans safe and secure. Efforts to reduce the deficit since FY 2010 have disproportionately relied on spending cuts on NDD programs and for FY 2016, the sequestered spending cap for NDD is already 17 percent below FY 2010 levels. As a share of our nation's economy or GDP, these programs are on track to their lowest level on record since 1962.

**Health and Human Services:** Cuts to NDD programs have significantly impacted agencies within the HHS, resulting in harmful impacts to the public health and its infrastructure, and scientific and medical research. Ultimately these cuts do no remedy important long term federal spending, particularly healthcare, which is slated to account for nearly one-fifth of the economy by 2021 and is a result of both an aging baby boomer population and chronic disease.

While continuing to provide coverage is essential, to truly lower the cost of healthcare spending in this country, Congress must invest in federal scientific and medical research so that cures are accelerated to market. This will ensure better results for patients and provide insight into what treatments and delivery services serve patients best, saving valuable healthcare dollars currently wasted on inappropriate and ineffective treatments. Every dollar invested in medical research outweighs the cost many times over and is, perhaps, the single most cost effective strategy in reducing our federal healthcare spending enabling us to sustain it for generations to come. Past investments in medical research has shown that biological sex impacts every organ of the body, and plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex, gender, and racial and ethnic diseases are evident in all major disease categories. Being biologically female or male can substantially impact drug absorption, distribution, metabolism

and elimination. Congress must ensure that all research conducted at or through funds provided by our federal health agencies and data generated maximizes its benefit and analyzes by sex, race, and other subgroup population demographics so that physicians can and will tailor treatments to meet the needs of individual patients.

The President's budget prioritizes this type of research, and allocates increases for the ARHQ and HRSA. These agencies, often overlooked by the American public, serve a vital role in evaluating and improving access to our health care system. With millions of Americans newly insured under the Affordable Care Act, we must ensure that they receive the best care possible. **SWHR urges the Committee to appropriate the President's request of \$479.3 million to AHRQ, and \$10.4 billion to HRSA.**

SWHR was pleased to see that the President's budget request provided substantial increases to SAMHSA and the CDC. These two agencies function as safeguards to protect Americans, and have been chronically underfunded for years. **SWHR supports the President's increase of \$44.6M over FY15 levels for SAMHSA; this includes \$103 million for strengthening the mental health crisis system, addressing prescription drug and opioid abuse, expanding the behavior health workforce, and fostering tribal behavioral health.** Similarly, the CDC serves as the nation's first line of defense in protecting Americans from infectious diseases from Ebola to antibiotic resistance (AR). The CDC's Office of Women's Health (OWH) has vital programs which increase the use of preventive services for women and children. **SWHR supports the President's request of \$7.010 billion for FY2016, and asks that the OWH within CDC receive \$600,000 for its work.**

*Health and Human Services' Offices of Women's Health* -The HHS OWH is the government's

champion and focal point for women's health issues. It works to address inequities in research, health care services, and public education gaps, which have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed. **Considering the impact of OWH's women's health programs on the public, we urge Congress to provide an increase of \$1 million for this office, a total of \$41 million for FY 2016.** Additionally, each Agency within HHS has an office or position that does critical work, both individually and in collaboration with other offices and federal agencies, to ensure that women receive the appropriate care and treatments in a variety of different areas. **SWHR recommends that these offices be sufficiently funded to ensure that these programs can continue to provide much needed services to women and their families in FY 2016.**

**National Institutes of Health (NIH):** The NIH serves as the America's premier medical research agency and is the largest source of funding for biomedical and behavioral research in the world. Many of the medical advances in recent decades are direct results from bipartisan investments in the agency. Unfortunately, spending cuts combined with sequestration has meant that NIH's purchasing power to decrease by 23%. This number does not just impact NIH's campus in Bethesda, Maryland. Approximately 85% of NIH funding is spent in communities across the country, supporting over 400,000 non-federal scientists and technical personnel at more than 3,000 universities, medical schools, teaching hospitals, and research institutions. A lack of proper investment in medical research also significantly impacts the next generation of scientists and researchers. NIH grant funding has now fallen to an all-time low of 15%, putting American scientists out of work or forcing them to accept positions abroad, resulting in the loss of skilled scientists and researchers to Africa, Asia, and Europe, who continue to heavily invest in research. When funding is not renewed for ongoing research NIH loses the impact of previous investment,

as scientists are not allowed to finish projects. **SWHR recommends that Congress set, at a minimum, a budget of \$32 billion for NIH for FY 2016. Further we recommend that NIH's mandate on the inclusion of sex as a variable in basic research be expanded to examine sex in all phases of basic, clinical and medical research and that NIH provide guidance on its new policy to balance the inclusion of male and female cells, tissues, and animals in pre-clinical basic research.**

***Office of Research on Women's Health (ORWH)*** - ORWH is the focal point for coordinating sex differences research at NIH, and supports innovative interdisciplinary initiatives, the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and the Specialized Centers of Research on sex and gender factors affecting women's health, which focus on supporting female scientists and women's health and sex and gender differences research. **To allow ORWH's programs and grants to continue make their impact on the research community, Congress must direct that NIH continue its support of ORWH and provide it with a \$1 million dollar budget increase, bringing its FY2016 total to \$41 million.**

In conclusion, Mr. Chairman, we thank you and this Committee for its support for medical and health services research and its commitment to the health of the nation. We look forward to continuing to work with you to build a healthier future for all Americans.

**THE AMERICAN SOCIETY OF NEPHROLOGY**

**LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED  
AGENCIES SUBCOMMITTEE OF THE UNITED STATES HOUSE OF  
REPRESENTATIVES COMMITTEE ON APPROPRIATIONS**

**WRITTEN TESTIMONY IN SUPPORT OF INCREASED FUNDING FOR THE  
NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES  
AT THE NATIONAL INSTITUTES OF HEALTH**

**April 28, 2015**

The American Society of Nephrology (ASN) is the world's largest kidney health professional organization—representing 15,000 scientists, nephrologists, and other kidney health providers—and committed to advancing research and treatment options for the more than 20 million children, adolescents, and adults with kidney disease in the United States today. The society requests at least \$2.066 billion in funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). The society also requests an additional \$150 million per year over 10 years for NIDDK kidney research above the current funding level.

ASN believes these are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney



disease and improve therapies for patients would yield significant saving to Medicare in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition Medicare automatically provides coverage for regardless of age or disability. At an annual cost of \$35 billion—more than NIH's entire \$30 billion budget—the ESRD Program represents nearly 7 percent of Medicare's budget even though ESRD patients represent less than 1 percent of the Medicare population. Despite the staggering burden of kidney disease, NIH investments in kidney research are less than 1 percent of total Medicare costs for patients with kidney disease (\$585 million vs. \$80 billion in 2014).

The vast majority of federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK. Examples of critical discoveries arising from NIDDK-funded research are numerous.

For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial and ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and better treatment. The finding that African Americans with two variants of the APOL1 gene are likely to progress to kidney failure faster than other ethnicities paves the way for future research to unlock better preventive therapies and gene-based cures.

Recent findings from NIDDK's Chronic Renal Insufficiency Cohort (CRIC) Study are helping uncover why patients with kidney disease are at greater risk for heart disease, the leading cause of death among patients with kidney failure. Further research exploring the mechanisms for this development could lead to new interventions for preventing heart disease.

Scientists supported by NIDDK have pursued cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment, the society firmly believes that funding NIDDK is a sound investment to create jobs, support the next generation of investigators, and ultimately provide quality care that is less expensive in order to improve the public health of Americans.

Medical research is a major force in the economic health of communities nationwide: every dollar invested in medical research generates \$2-3 in economic activity. America must continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and remain the world leader in innovation and discovery—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact ASN Senior Policy and Government Affairs Associate Grant Olan at (202) 640-4657 or [golan@asn-online.org](mailto:golan@asn-online.org).

## **ABOUT ASN**

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 15,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at [www.asn-online.org](http://www.asn-online.org).

Testimony of the Tri-Council for Nursing  
Fiscal Year (FY) 2016 Appropriations for the Title VIII Nursing Workforce  
Development Programs  
U.S. House Appropriations Subcommittee on  
Labor, Health and Human Services, Education, and Related Agencies  
April 29, 2015

Submitted by Michelle Artz, Director of Government Affairs, American Nurses Association

The Tri-Council for Nursing, comprising the American Nurses Association, the American Association of Colleges of Nursing, the American Organization of Nurse Executives, and the National League for Nursing, respectfully requests **\$244 million in fiscal year (FY) 2016 for the Nursing Workforce Development programs authorized under Title VIII of the *Public Health Service Act* (42 U.S.C. 296 et seq.) and administered by the Health Resources and Services Administration.**

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. The members of these respective organizations are acutely aware of the demand for nursing services due to a growing aging population, an increased focus on preventative care, and skyrocketing rates of individuals with multiple chronic conditions.

According to the U.S. Bureau of Labor Statistic's *Employment Projections for 2012-2022*, the employment of registered nurses (RNs) is projected to grow 19 percent from 2012 to 2022. BLS also projects job openings for RNs due to growing demand and replacement needs in the workforce will be over 1 million by 2022.

Increasing demand in the coming years will be driven by an aging population. According to the Pew Research Center, an estimated 10,000 people a day are turning 65 and that trend will

continue until 2019. As such, the healthcare workforce will need to grow to keep up with demand for nursing care in traditional acute care settings and the expansion of non-hospital settings such as home care and long-term care. Further, more than one million of the nation's 2.6 million practicing RNs are over the age of 50, according to the *2008 National Sample Survey of Registered Nurses*.

Nurses continue to be the largest group of healthcare providers whose services are directly linked to quality and cost-effectiveness. The Tri-Council is grateful to the Subcommittee for its past commitment to Title VIII funding and respectfully asks that you continue to make the long-term investment that will build our nation's nursing workforce.

#### **Nursing Workforce Development Programs<sup>1</sup>**

Since 1964, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. These programs have supported nursing education at all levels and supported institutions that educate nurses who practice in rural and medically underserved communities. A description of the Title VIII programs is provided below:

Advanced Nursing Education (ANE) Programs (Sec. 811) fund a number of grant activities – including several traineeships – that aim to increase the size and quality of the advanced

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<sup>1</sup> U.S. Department of Health and Human Services. (2015). Health Resources and Services Administration Fiscal Year 2016 Justification of Estimates for Appropriations Committees. Retrieved from: <http://hrsa.gov/about/budget/budgetjustification.pdf>.

nursing workforce. Supporting the preparation of RNs in master's and doctoral nursing programs, the ANE grants help prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health nurses, and other nursing specialists requiring advanced nursing education. In Academic Year 2013-2014, these grants supported the education of 10,504 students.

Under the ANE program are two critical traineeship programs that are particularly relevant as the demand for primary and acute care services rises. The Advanced Education Nursing Traineeships (AENT) assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees, and reasonable living expenses. The Nurse Anesthetist Traineeships (NAT) support the education of students in nurse anesthetist programs. In some states, certified registered nurse anesthetists are the sole anesthesia providers in nearly 100% of rural hospitals. In Academic Year 2013-2014, the AEN Traineeship and the NAT supported 5,650 nursing students, exceeding the program's target of 2,910.

Nursing Workforce Diversity (NWD) Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. This program awards grants and contract opportunities to schools of nursing for clinical training to address nursing educational needs. In Academic Year 2013-2014 the number of NWD student trainees was 6,691.

Nurse Education, Practice, Quality and Retention (NEPQR) Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health clinics, as well as state and local governments strengthen nursing education programs, thereby increasing the size and quality of the nursing workforce. The purposes of the NEPQR grants are broad and flexible, allowing the program to address emerging needs in nursing workforce development. NEPQR supports infrastructure development to enhance the coordination and capacity building of inter-professional practice and education among health professions across the United States, and particularly in medically underserved areas.

NURSE Corps (Sec. 846), (formerly the Nursing Education Loan Repayment and Scholarship Program) provides support for nurses and nursing students to alleviate nursing shortages and ensure access to nursing services in underserved areas. The NURSE Corps Scholarship Program provides qualified individuals with tuition support and a stipend provided they serve at a Critical Shortage Facility upon graduation. Participants in the NURSE Corps Loan Repayment Program can have up to 85 percent of qualifying loans forgiven. Registered nurses and advanced practice registered nurses are eligible if they serve two or three years at Critical Shortage facilities and nurse faculty employed at accredited nursing programs also are eligible. In FY 2014, the NURSE Corps Programs supported 1,334 nurses.

Nurse Faculty Loan Program (Sec. 846A) increases the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing. Students agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans,

plus interest, over a four-year period. In Academic Year 2013-2014, this program supported a total of 2,401 nursing students pursuing a graduate-level degree as nurse faculty.

Comprehensive Geriatric Education Program (Sec. 865) provides support to nursing students specializing in care for the elderly. The program may also fund traineeships for individuals who are preparing for advanced education nursing degrees in geriatric nursing, long-term care, geropsychiatric nursing, or other nursing areas that specialize in the care of the elderly population. In Academic Year 2013-2014, there were 14,200 trainees supported by these grants.

Nurses are the key to helping decrease healthcare costs, addressing the burden of disease, and improving the quality of care delivery. The funding of federal programs that have proven their effectiveness over many years, such as Title VIII Nursing Workforce Development programs, helps ease the demand for RNs. The Tri-Council respectfully requests your support for \$244 million in FY 2016 for the Title VIII Nursing Workforce Development Programs. If our organizations can be of assistance, please contact ANA's Director of Government Affairs, Michelle Artz, at [michelle.artz@ana.org](mailto:michelle.artz@ana.org) or (301) 628-5098. Thank you in advance for providing these resources to bolster the nation's nursing workforce.



**Testimony of the Physician Assistant Education Association (PAEA)  
Concerning HRSA's Title VII Health Professions Programs**

*Submitted for the Record to the House Appropriations Subcommittee on  
Labor, Health and Human Services, Education and Related Agencies – April 29, 2015*

*Submitted by: Anthony Miller, M.Ed., PA-C Chief Policy and Research Officer  
tmiller@paeaonline.org, 703-667-4339*

On behalf of the 196 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year (FY) 2015 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least \$280 million in FY 2016 for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). We also request \$12 million of that funding support PA programs operating across the country. This is the only designated source of federal funding for PA education and is crucial to the U.S. PA education system's ability to meet the demand for education and to continue to produce highly skilled physician assistants ready to enter the health care workforce in an average of 26 months. The way that PAs are educated in America – the caliber of our institutions and the expertise of our educators – is the gold-standard throughout the world and that distinction must be maintained in this period of unprecedented patient need and rapid growth within the PA profession.

**Need for Increased Federal Funding**

The unmet need for primary care services in the United States is well documented, and only expected to grow as Baby Boomers age and require more health care services and as formerly uninsured patients gain access. Health care systems are rapidly evolving, yet the one constant remains the need for qualified health care providers in numbers sufficient to meet demand. Primary care has been clearly identified as the critical entry point into the health care system where that access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost fifty years ago; and today's PAs stand ready to help address the challenges our nation faces in primary care and other specialties. The effectiveness of physician assistants is well-documented by studies showing better patient access, especially for Medicaid patients, high patient satisfaction, more frequent patient education, and health care outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care if offered appropriate financial support and through innovations in the PA education system.

Like physicians, the PA profession also faces a shortage of graduates that will hinder its ability to help fully address the primary care issue in the United States. Without new solutions, at the current output of approximately 8000 graduates from PA programs per year, these shortages will persist, particularly in the rural and underserved communities where care is needed the most. Title VII is the only funding source that provides direct support for PA programs and plays a crucial role in developing and supporting the education system's ability to produce the next generation of these advanced practice clinicians.

### **Background on the Profession**

Since the 1960s, PAs have consistently demonstrated they are effective partners in health care, readily adaptable to the needs of an ever-changing delivery system. Physician assistants are licensed health professionals with advanced education in general medicine that practice medicine as members of the healthcare team. They provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings, including prescriptive authority in all 50 states, the District of Columbia, and Guam. PAs practice medicine to the extent allowed by law and within the physician's scope of practice and their combination of medical training, advanced education, and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas where they are often the only full-time medical provider. The profession is well established, yet nimble enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges. The PA practice model is, by design, a team-based approach to patient-centered care where the PA works in tandem with a physician and other health professionals. This PA practice approach to quality care is uniquely aligned with the patient-centered, collaborative, interprofessional and outcomes-based care models transforming the U.S. health care system.

### **PA Education: The Pipeline for Physician Assistants**

There are currently 190 accredited PA education programs in the United States. Together these programs graduate over 8,000 PA students each year. PAs are educated as generalists in medicine and that training gives them the flexibility to practice in more than 60 medical and surgical specialties. More than one third of PA program graduates are working in a primary care specialty.

The average PA education program is 26 months in length and includes one didactic year in the classroom, and another year devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical training, second only to physicians in time spent in clinical study.

As of today, approximately 77 new PA programs are in the pipeline at various stages of development and moving toward accredited status. The growth rate in the applicant pool is even more pronounced. Since its inception, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2015, there were 22,997 applicants to PA education programs, which represents a 35% increase in CASPA applicants over the past five years alone.

The PA profession is expected to continue to grow as a result of the projected shortages of physicians and other health care professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. Accordingly, The Bureau of Labor Statistics projects a 39% increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well positioned to help fill projected shortages in the numbers of health care professionals—if appropriate resources are available to support the education system behind them.

## AREAS OF ACUTE NEED

### Faculty Shortages

Faculty development is one of the profession's critical needs and educators are an often overlooked element to developing an adequate primary care workforce. Nearly half of PA program faculty are 50 years or older and the PA teaching profession faces large numbers of retirements in the next 10-15 years. An interest in education must be developed early in the educational process to ensure a continuous stream of educators, and to do so, we must alleviate the significant loan burdens that prevent many physician assistants from entering academia. In order to attract the most highly qualified faculty, PA education programs must have the resources to help clinicians transition into education, including curriculum development, teaching methods, and laboratory instruction. Most educators come from clinical practice and these non-clinical professional skills are essential to a successful transition from clinical practice to a classroom setting. Without federal support, we will face an impending shortage of educators who are prepared for and committed to the critical teaching role that will ensure the next generation of skilled practitioners.

### Clinical Site Shortages

Outside of the classroom, PA education faces additional challenges in meeting demand. A lack of clinical sites for PA education is hampering PA programs' ability to produce PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals (preceptors) willing to teach students as they are cycling through their clinical rotations, and a lack of sites with the physical space to teach. Cutbacks in federal and state funding of Area Health Education Centers (AHECs) has also contributed to reduced access to clinical training for PA students, particularly in rural and underserved communities.

This phenomenon is experienced throughout the health professions, and is particularly acute in primary care. It has created unintentional competition for clinical sites and preceptors within and among PAs, physicians and advance practice nurses. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for PAs and other health professionals to train together and directly interact with patients as a team. PAEA believes that interprofessional clinical training and practice are necessary for optimum patient care and will be a defining model of health care in the U.S. in the 21st century. We can only make that a reality if we begin to build a sufficient network of health professionals who are willing to teach the next generation of primary care professionals—that approach will benefit PAs as well as the future physicians, nurses and other clinicians that comprise the full primary care team.

### Enhancing Diversity

Workforce diversity, and practice in underserved areas are key priorities identified by HRSA and are consistent with those of PAEA. It is increasingly important for patient care quality that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, including veterans who have served our country and desire to transition to civilian health professions. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care, and PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field. If we can

provide resources to schools that are particularly poised to improve their diversity recruitment efforts and replicate or create best practices including transition programs for our veterans, we can begin to address this systemic need.

In order to leverage the efforts of PA programs through Title VII funding to increase workforce diversity in the PA profession, PAEA also supports funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps (NHSC). Historically, access to higher education has been constrained for individuals from disadvantaged backgrounds. These programs help to provide a clear path for students who might not otherwise consider a physician assistant career.

#### **Title VII Funding**

Title VII funding fills a critical need for curriculum development, faculty development, clinical site expansion and diversification of the primary care workforce—areas that if appropriately supported can help ensure the PA profession realizes its full promise in the U.S. health care system. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enable innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients with the most urgent need for access to care.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the Appropriations process specifically for PA programs working to address the health provider shortage. This funding has enhanced capabilities to train a growing PA workforce, creatively expand care to the underserved, and develop a more diverse PA workforce:

- One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.
- An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a four-week comprehensive educational program in HIV disease diagnosis and management.
- A New York program is using its PA training grant to operate a mobile health vehicle to provide health education and initial health screenings to local underserved communities. The experience has motivated students to enter primary care; the direct exposure achieved by utilizing a mobile health vehicle provides the communities with medical and preventive education and health screenings while also addressing the students' awareness of cultural competency and health literacy.
- A Virginia program uses its PA training grant to support transitioning veterans, while increasing the placement of graduates in primary care and medically underserved communities. The grant allows the PA program to provide scholarship to incoming physician assistant students who are veterans, and who dedicate the beginning of their careers to a primary care setting

**Recommendations on FY 2016 Funding**

The Physician Assistant Education Association, along with the support from our colleagues in the health professions community, requests the Appropriations Committee's support in funding for Title VII health professions programs at a minimum of \$280 million for FY 2016. This level of funding is crucial to support the nation's ability to produce and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and the military who will practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care cluster. The Accreditation Review Commission on Education for the Physician Assistant (ARC-PA) estimates that an additional 77 programs will be added by 2020. Therefore, we request an increase in funding to \$12 million which will allow sufficient funding for the expanding number of PA programs expected to begin enrolling students during the next four to five years.

We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's FY 2016 funding recommendation.

Thomas Bengaff

Board Member, Heightened Independence and Progress (CIL)

As a quadriplegic living independently in 'independent living' and a member of the board of directors of hip (Heightened Independence and Progress) a successfully led CIL by Eileen Goff, our profoundly blind CEO, I think I'm in a position to advise you. Our CIL has helped families and people with disabilities remain whole and happy through many of our programs and facilities. We provide information, support and at times things such as air-conditioners, Christmas gifts and even jobs.

<http://hipcil.org/>

I support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS budget for Centers for Independent Living (CILs). I am asking that you increase funding by \$200 million, for the Independent Living line item in FY 2016.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 356 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and the newly added transition services. From 2012-2014, CILs provided the four core service to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals.

Transition services were added as a fifth core service with the passage of the Workforce Innovation and Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2015, the Independent Living Program is receiving nearly \$3 million less in funding

than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,

Thomas Bengaff  
81 Rivervale Road, 1-1A  
River Vale, NJ 07675



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